

Supported self-management: a novel cancer survivorship care pathway

A phase I/II intervention study with
cancer survivors in New Zealand

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UNIVERSITY OF OTAGO WELLINGTON

Department of Public Health

Inga O'Brien

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Abstract

More people are living with, through and beyond cancer which makes cancer survivorship an increasingly important area of public health focus. Cancer survivors manage cancer and treatment-related health impacts and life complexity during and post-treatment. These cancer-related impacts, whether visible or invisible, can cause intermittent yet considerable problems. Cancer survivorship research explores ways to improve care and management for people living with, through or beyond cancer.

Evidence-based intervention is a fruitful area for cancer survivorship research. Intervention can inform survivorship care pathways. Chronic care approaches have not been adequately explored as a basis for survivorship intervention. Using Te Whare Tapa Wha and Wagner's Chronic Care Model as theoretical frameworks, the application of supported self-management programs in cancer care is explored herein. This thesis reports on survivorship experiences and a pilot study of a supported self-management intervention program for cancer survivors in New Zealand (NZ).

Background: The objectives of this thesis are to report on NZ cancer survivors' experiences and explore the acceptability, feasibility and pilot delivery of a supported self-management program. Supported self-management intervention programs aim to empower and support people living with chronic conditions to navigate social, physical, emotional and spiritual impacts associated with chronic disease management. The supported self-management intervention program chosen for trial, The Flinders Program, is tailored based on self-assessment surveys and guided interviews/sessions. It results in development of a care plan and, ideally, improved wellbeing. To date, supported self-management programs have not been trialled in NZ as a component of cancer care survivorship pathways that emphasise wellbeing.

Methods: The purpose of this study was to explore NZ survivors, as well as health and supportive care workers', experiences of cancer treatment impacts and care gaps. A supported self-management intervention program was delivered in a NZ hospital setting to see if it could acceptably and feasibly address cancer survivor impacts and unmet needs. A Medical Research Council (UK) framework guided the two-phase study design. The pilot was limited to patients diagnosed with colorectal cancer because these cancers are common in NZ and intervention with colorectal cancer survivors is comparatively under-researched. The first phase of the study qualitatively explored the lived experiences of survivors and the views on survivorship held by a selection of health and supportive care

workers. The data showed unmet survivor needs, existing self-management strategies employed, and possible acceptability of The Flinders Program. The second phase of the study piloted The Flinders Program with cancer patients over three sessions coinciding with standard appointments during treatment. Phase two aimed to test the feasibility of procedures for recruitment, randomisation, intervention delivery and outcome evaluation in outpatient cancer clinics. The intervention was delivered using a two-arm pre- post-assessment design to inform intervention acceptability and feasibility. Process evaluation explored enablers/ barriers of intervention delivery while distress, resilience, self-efficacy and quality of life patient-reported outcomes were assessed.

Results: The MRC Framework on complex interventions provided a strong structure for conducting planned and stepped intervention research. The phase one qualitative study findings were that both Māori and non-Māori cancer survivors experienced social, physical, emotional and spiritual impacts through cancer treatment that affected their ability to self-manage effectively during active treatment and in the post-cancer treatment transition and extended survival period. Survivor impacts were managed through survivorship work. Phase one data indicated cautious acceptability of The Flinders Program. Phase two data showed that the supported self-management intervention program is questionably feasible, but had the potential to contribute to improved self-management competence if issues related to enablers and barriers at the individual (i.e. self-management readiness) and environmental levels (i.e. staff resourcing) could be addressed.

Discussion: A Chronic Care Model-based supported self-management intervention, The Flinders Program, can be delivered in cancer care settings to address survivorship impacts. However, there are important differences between the setting of chronic conditions and the cancer clinical setting as identified by survivors' shared experiences. The Flinders Program was deemed acceptable to both Māori and non-Māori survivors as well as health and supportive care workers participating in the pilot study but there were feasibility challenges associated with delivering the program in hospital-based cancer treatment settings. The Flinders Program did impact on patient-reported outcome measures but in no clear significant pattern or consistent manner. Further intervention research into supported self-management programs or other types of survivorship care is needed to progress survivorship care pathways.

Acknowledgements

This thesis is the result of interactions I have had with cancer survivors through my work in the field of cancer survivorship. I am especially grateful to those who participated in this study. Thank you very much. By sharing your story, I truly believe that it will make a difference and contribute to improved cancer care for those living with, through or beyond cancer in the future.

I had thought about doing a PhD for many years before I embarked on this 6-year odyssey. I was convinced by Professor Barry Borman, Dr Mona Jeffreys and Dr Fiona McKenzie to go ahead. This research project initially developed out of cancer patient and survivor experience work that I began in my previous role at Cancer Control New Zealand. My colleagues encouraged me to extend that work to help address gaps in cancer care that were reflected in those shared survivor experience accounts. I would also like to acknowledge Dr Greg Martin, Professor Jackie Cumming, Dr Jaiki Desai and Associate Professor Richard Arnold for their understanding and support during my transition of study from Victoria University to University of Otago (UOW) Wellington during my first year.

A UOW postgraduate scholarship enabled me to pursue this study and thesis full-time for two years and then part-time over the last four years. I would like to thank my UOW-based support staff. Special thanks to my doctoral supervisors Professor Diana Sarfati and Associate Professor Louise Signal. I also wish to acknowledge the invaluable writing support provided by Karen Johnson and Emma Osborne as well as the statistical support provided by Dr James Stanley. My colleagues, Anaru Waa and Jeannine Stairmand, provided practical research support and encouragement for which I am thankful. I had the privilege of accessing additional support from a dedicated group of advisors including Dr Lis Ellison-Loschmann, Dr Anne O'Donnell, Ms Liz Dennett, Ms Pauline Wharerau and Dr Janine Bycroft. Special gratitude to all the staff at the Wellington Blood & Cancer Centre and my colleagues at the Cancer Society.

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I'd like to dedicate this thesis to my late grandmother, Allie, and my mother, Lynn, who were my best sources of inspiration for carrying on when the going got tough. I felt that they were instrumental in putting the right people and resources in my path to fulfil my dream of completing this thesis.

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My fellow post-graduate students and amazing friends offered distraction and great advice in turns through many cups of coffee, office chats and presentation days. There were numerous others not mentioned here who helped me along the way and I am indebted to everyone who showed their faith in me.

My children are incredible. I feel we are proud of each other for who we are together as a family and for what we choose to do as individuals. My daughter, Medea, was steadfast in her faith in me when the going got tough. She often quoted Dory to me "Just keep swimming, Mum". My son, Conory, helped me remember that humour truly is the best medicine. I feel so blessed to be their Mum and hope they know that I am proud of them each day.

Statement of participation

This thesis aligned with a large two-part program of work conceived by Professor Diana Sarfati; the Cancer, Care and Comorbidity (C3) projects. Each of my thesis supervisors led a part of the program. Professor Sarfati led the quantitative methods part and Associate Professor Signal led the qualitative methods part. The overall hypotheses of the two C3 projects were that: 1) comorbidity has a measurable negative impact on treatment quantity and quality, and cancer survival among cancer patients in New Zealand; 2) Māori diagnosed with cancer receive both a lesser quantity and quality of treatment, and consequently have worse survival than similar non-Māori people with cancer with the same level of comorbidity; and 3) substantial improvements in health outcomes are possible for all, and particularly for Māori, if treatment quality and quantity meet the best standards for all (Signal 2015; Sarfati 2015).

The work presented in this thesis was developed and carried out by me to consider intervention to translate research into practice that could improve health outcomes. The intervention studied and reported on was intended to encompass comorbidity yet potentially improve cancer care in NZ. All data used in this thesis was collected for addressing the questions posed in this thesis.

I initiated the two-phase intervention study, obtained funding for it, and led it as Principal Investigator. I also developed the protocols for both the phase one and phase two studies. Anaru Waa and Associate Professor Louise Signal assisted with facilitation of focus groups in phase one. Stephen Keating transcribed the interviews and focus group recordings. I analysed the qualitative data. Joanne Gregg and Jonathan Barrett were hired as contract research assistants to do the follow-up assessments for the phase two study. Dr James Stanley assisted with the data analysis and graphical display of the data for the phase two pilot study. I was involved in all aspects of quantitative data analysis.

Additional project advice was sought on specific issues. Advisors included Dr Lis Ellison-Loschmann, Dr Janine Bycroft, Dr Anne O'Donnell, Ms Liz Dennett, Cathie Teague, Caroline Stafford and Catherine Birch. Additional consultation was undertaken with the C3 project and Māori advisory groups as well as the Cancer Society's cancer information nursing team.

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Abbreviations

ABCC	Alleviating the Burden of Chronic Conditions in New Zealand Study (The ABCC NZ Study)
ASCO	American Society for Clinical Oncology
CBT	Cognitive Behaviour Training or Therapy
C3	Cancer, Care and Comorbidity project
CDSMP	Chronic Disease Self-Management Program
DHB	District Health Board
FHBHRU	Flinders Human Behaviour and Health Research Unit (Australia)
GP	General Practitioner
HEAT	Health Equity Assessment Tool
IOM	The Institute of Medicine (USA)
IPOS	International Psycho-Oncology Society
KOETI	Kia Ora E Te Iwi
NHS	National Health Service (UK)
NZ	New Zealand
MRC	The Medical Research Council (UK)
NCCN	National Comprehensive Cancer Network (USA)
NICE	National Institute for Clinical Excellence (UK)
PoCoG	The Psycho-oncology Co-operative Research Group (Australia)
QOL	Quality of life
RCT	Randomised controlled trial
USA	The United States of America
UK	The United Kingdom
UOW	University of Otago Wellington
WHO	World Health Organization

Glossary of Māori terms

The following Māori terms are used in this thesis. The English definitions are sourced from Moorfield's (2005) online Te Aka Māori-English, English-Māori Dictionary.

Aotearoa	North Island - now used as the Māori name for New Zealand
Aroha	affection, sympathy, charity, compassion, love, empathy
Hauora	be fit, well, healthy, vigorous, in good spirits
Hinengaro	mind, thought, intellect, consciousness, awareness
Iwi	extended kinship group, tribe, nation, people, nationality, race - often refers to a large group of people descended from a common ancestor and associated with a territory
Kaupapa	topic, policy, matter for discussion, plan, purpose, scheme, proposal, agenda, subject, programme, theme, issue, initiative
Kaupapa Māori	Māori approach, Māori topic, Māori customary practice, Māori institution, Māori agenda, Māori principles, Māori ideology - a philosophical doctrine, incorporating the knowledge, skills, attitudes and values of Māori society
Koha	gift, present, offering, donation, contribution
Mana	prestige, authority, control, power, influence, status, spiritual power, charisma - <i>mana</i> is a supernatural force in a person, place or object. <i>Mana</i> goes hand in hand with <i>tapu</i> , one affecting the other. The more prestigious the event, person or object, the more it is surrounded by <i>tapu</i> and <i>mana</i> .
Manaaki	show respect
Māori	Māori, indigenous New Zealander, indigenous person of Aotearoa/New Zealand
Pākehā	English, foreign, European, exotic - introduced from or originating in a foreign country
Pono	truth, non-fiction, validity

Tangata whenua	local people, hosts, indigenous people - people born of the whenua, i.e. of the placenta and of the land where the people's ancestors have lived
Tangata tiriti	The people of the Treaty of Waitangi, non-indigenous New Zealanders
Tinana	body, trunk (of a tree), the main part of anything.
Tapa	to call, name, recite
Tapu	be sacred, prohibited, restricted, set apart, forbidden, under <i>atua</i> protection
Tautoko	support
Tika	truth, correctness, directness, justice, fairness, righteousness, right
Tikanga	correct procedure, custom, habit, lore, method, manner, rule, way, code, meaning, plan, practice, convention, protocol - the customary system of values and practices
Waiora	health, soundness
Wairua	spirit, soul
Whā	be four, 4
Whakama	to lose mana, to be ashamed, shy, bashful, embarrassed
Whakamana	to give authority to, give effect to, give prestige to, confirm, enable, authorise, legitimise, empower, validate
Whakawhānaungatanga	process of establishing relationships, relating well to others
Whakapapa	genealogy, genealogical table, lineage, descent
Whānau	extended family, family group, a familiar term of address to a number of people. In the modern context the term is sometimes used to include friends who may not have any kinship ties to other members.
Whare	house, building, residence, dwelling, shed, hut, habitation, suit
Wheke	octopus, squid - a general term, particularly for octopuses

Glossary of terms

The following terms are used to identify categories of people described in this thesis.

Cancer survivor	Someone living with, through or beyond cancer.
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The definition of the following terms comes from the He Anga Whakaahuru: Supportive Care Framework (Central Cancer Network 2016) document.

Health and supportive care workers	Term used to apply to anyone working the health system and non-government organisations (NGOs) as well as those working in social care agencies who may have contact with a person who is affected by cancer.
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Person affected by cancer	Term used to refer to both the person with cancer and those for whom the cancer has an impact.
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Whānau	Māori term used to refer to both descent-based whānau and whānau who come together for a common purpose. Metge (1995) defines the two kinds of whānau as whakapapa-based whānau and kaupapa-based whānau. This acknowledges that for people, their whānau can be both their family of descent as well as those people they define as important who make up their support network.
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Declarations

I declare that this report is of original authorship and is the intellectual property of the author. I foresee no cultural, social or legal impediments to publication of this report.

CHAPTER 1: Introduction

Cancer survivors share the unlucky experience of being diagnosed with cancer. Cancer incidence is rising due to an ageing population; however, so is survival. Attributed most commonly to earlier detection and better treatment options, cancer no longer tops the list of acute self-limiting diseases. Overall, the numbers of people living with, through or beyond cancer are increasing. Hence, there are increasing numbers of cancer survivors in the general population.

Cancer survival comes at a cost. Cancer survivors report intermittent, yet often lingering, impacts related to the cancer itself and various treatments. These ongoing problems can affect wellbeing. These problems, as reported by cancer survivors, include fatigue, sleep difficulty, fear of recurrence, anxiety, depression, negative body image, sensory neuropathy, gastrointestinal problems, urinary incontinence, and sexual dysfunction (Denlinger and Barsevick 2009). Care pathways that deliver evidence-based intervention for cancer survivors can promote wellbeing and help support survivors to address the problems they experience living with, through and beyond cancer.

There is a huge diversity and complexity in survivors' experiences and care needs globally. My interest in this topic was triggered by the results which emerged from the 2009 NZ national cancer patient experience survey (O'Brien et al. 2010). Unmet survivorship needs were identified; particularly apparent were the ongoing everyday life impacts described in response to the two open-ended questions on respondent experiences. Three reports (Cancer Control Council of New Zealand 2009; Cancer Control New Zealand 2010; Cancer Control Council of New Zealand 2010) and two journal articles (O'Brien et al. 2010; Britton et al. 2010) were written from the data.

The unmet needs and perceived gaps in cancer care reported in the NZ literature indicate the need for further research to address survivorship care (Cormack et al. 2005; Dew, Signal et al. 2015; Egan et al. 2014; Doherty 2006; Ministry of Health and University of Otago 2010; Sarfati, Koczwara, and Jackson 2016; Walker et al. 2008). In the early stages of this research, my aim was to raise awareness of the experiences of survivorship as well as contribute to quality improvement in NZ cancer care delivery.

As my research planning progressed, I gained more clarity on the role of cancer survivorship and the need for further research to address care pathways that lie within and beyond the acute stage of diagnosis and treatment. Overseas research affirms that

survivors can face life-long health risks and challenges as a result of their cancer and its treatments (Oeffinger et al. 2014; Hewitt, Greenfield, and Stoval 2006; National Institute for Clinical Excellence 2004). These include physical and psychological functioning limitations that affect everyday life and feelings of wellbeing. The USA, UK, Canada and Australia have undertaken demonstration projects to inform care pathway redesign to address health risks and challenges faced by survivors (Halpern et al. 2014; Jefford et al. 2013; Jefford et al. 2015; National Cancer Survivorship Initiative 2010). A clearer study direction for me, based in the survivorship space, emerged out of my review of the literature. The literature review identified a gap in NZ-based survivorship demonstration projects. Further, no international survivorship demonstration projects have yet been seamlessly integrated into redesigned care pathways overseas. Therefore, this project can add to the rapidly evolving practice and knowledge base for improved survivorship care.

I am a non-NZ born, non-indigenous researcher who has adopted NZ for my family's home. This study applied my leanings toward self-determination based on my upbringing as an adoptee in an immigrant family living in the USA. My brother had special needs and my main caregiver managed severe allergies. We spent a lot of time in medical clinics. This experience impressed upon me the need for support that integrated people's social reality with clinical advice and care delivery.

I hope to contribute to practical research that could benefit New Zealanders. In NZ, colorectal cancer is one of the most prevalent cancers. However, colorectal cancer survivor cohorts are under-represented in NZ research. More research is needed to identify and evaluate interventions that can assist individuals and whānau living with, through and beyond colorectal cancer in NZ to collaboratively manage treatment and ongoing survivorship needs.

An important point that needed consideration was my ability to conduct robust research as an 'insider' in cancer care. I have worked in cancer clinics and as a senior analyst for Cancer Control NZ. I currently manage supportive care services at the Cancer Society of NZ. Therefore, I am not a detached and neutral objective outsider in this field. This poses risks to research validity and can introduce bias (Crotty 1998). On the other hand, an insider brings advantages to research in that networks are established, terminology and technical understanding already has a base, and rapport based on familiarity with some shared experiences can be more readily achieved (Rooney 2005).

Considering my insider status and non-resident status, it was important that I practice reflexivity to conduct this research with critical awareness of the filters, shaped by my own experiences, culture and history, through which I made sense of the collected data. Reflexivity can help mitigate potential bias or threats to validity (Brannick and Coghlan 2007). A colleague recommended a checklist as a basis for reflexive practice which included paying attention to personal motivations, choices about participants, emotional status, surprising findings, presenting findings neutrally and exploring why emphasis was being placed in some areas if there were signs of bias (Robson 2002; Robson 2011).

I attempted to practice in a neutral and culturally safe manner to minimise any real or perceived power imbalances between researcher and research participants in this study. The research process was designed to be empowering and incorporate principles of indigenous research practice including prioritisation of Māori and commitment to transformative practices that can address inequities (Health Research Council of New Zealand 2010; National Ethics Advisory Committee 2012). To achieve this, I received invaluable advice from Māori study advisors.

There is not likely to be a 'one-size fits all' survivorship care pathway waiting to be discovered, considering the diversity of people in NZ. This pilot study explored one interventional approach that integrated consideration of environmental factors and drivers. Previous studies have shown that single, short-term, supportive care or survivorship interventions are typically unable to sustain long-term improvements in clinical or patient-reported outcomes for survivors. Over the last few years I have sought a simple answer: the single, predefined intervention that can work. My critique of the literature highlighted that prescribed, decontextualized, one-off interventions do not seem to align with human behaviour and often fail. Multi-faceted interventions that allow tailored approaches based on assessment of person-led priorities and recognition of complexity are gaining acceptance across public health interest areas. Tailored interventions seem to be one way to avoid oversimplification and associated intervention failure.

Supported self-management intervention can be delivered as a tailored program¹, using a combination of strategies and tools. Research into this interventional approach can add to the knowledge and practice base for delivery of person-centred, integrated and

¹The spelling of the word programmes is often shown as 'programs' throughout this thesis because the trademarked intervention delivered, The Flinders Program, uses that spelling and the use of a consistent spelling of that word throughout the thesis aims to reduce complexity and avoid confusion for the reader.

collaborative survivorship care. The supported self-management intervention program piloted and described in this thesis incorporates various other interventions, tools and strategies tailored to survivors' and families' complexities and identified values, priorities and goals. The umbrella term 'supported self-management program' is most commonly associated with tailored approaches that integrate various tools and techniques. This thesis describes development of evidence for an outpatient clinic-based supported self-management intervention program with, and for, Māori and non-Māori people affected by colorectal cancer in NZ. It explores the acceptability, feasibility, utility, and appropriate timing and setting for this type of survivorship intervention in NZ.

Research questions

The research questions guide the research which explores NZ survivors' cancer experiences and delivery of a supported self-management intervention program in hospital-based cancer clinic settings.

1. What are cancer impacts and how are they experienced by survivors in NZ?
2. What other factors contributed to life and health complexity, and coping for NZ cancer survivors?
3. Can a supported self-management intervention help address cancer and complexity impacts for survivors?
4. Is a supported self-management program acceptable in outpatient cancer care settings?
5. Can a supported self-management intervention program be feasibly integrated into the outpatient cancer treatment setting?

Study objectives

Two studies were conducted to address the research questions. The aim of the phase one study was to qualitatively explore survivors' and clinicians' experiences and views. The aim of the second study was to pilot the acceptability and feasibility of a supported self-management intervention program in cancer care settings.

The specific phase one objectives were to:

- Qualitatively explore, with survivors and health professionals, cancer treatment impacts, life and health complexity, as well as management strategies utilised by NZ cancer survivors during and post-treatment; and,
- Use an intervention vignette to gauge the perceived acceptability of The Flinders Program, a supported self-management program, in the NZ hospital-based cancer clinical setting.

The specific phase two objectives were to:

- Test study design aspects of recruitment, randomisation, intervention delivery and assessment by linking in with clinical flow in cancer care clinics;
- Provide insights into supported self-management program content as well as enablers and barriers to intervention delivery in the context of cancer survivorship;
- Explore and compare outcome measures of self-efficacy; and, measures of global quality of life, distress, resilience and patient experience.

Philosophical perspective

Methodology and theoretical orientation, which flow from philosophy, have led to the choice of specific research methods to address the objectives of this research. Aspects of philosophy explored included epistemology or the nature of knowledge, ontology or the nature of being, and axiology or the assignation of value. In consideration of my views on what is knowledge, what is reality and what is of value, my chosen approach was pragmatic.

Pragmatism is identified with research into 'what works, under what circumstances' (Mertens et al. 2010) and explores practical consequences (Creswell and Plano Clark 2010). It is practical and fits with a critical realist worldview that considers an objective 'truth' or reality but recognises that there are different perspectives on truth and that experienced 'reality' is a type of subjective truth (Mertens et al. 2010). Pragmatism bridges the duality between objective and subjective realities.

Mixed methods is a data collection technique that complements pragmatism. It combines quantitative and qualitative methods. Just as designing a research study is both art and

science, the lines between methods of inquiry are not always mutually exclusive (Patton, 2002,12). In this study, both qualitative and quantitative methods were applied and the studies took place sequentially.

Thesis structure

This introductory chapter provides a brief context for this thesis.

Chapter 2: Background is a foundational chapter presented in three parts. In part one, the NZ experience of cancer and the various stages and challenges associated with cancer treatment are described, with emphasis on colorectal cancer. Part two explores cancer impacts and the experience of cancer as a chronic condition. An overview of The Chronic Care Model (Wagner et al. 1996) is provided as the framework to guide the choice of intervention. Part three provides an overview of healthcare intervention, and introduces a guiding intervention framework (Medical Research Council 2009), and specific considerations indicated for intervention delivery in NZ.

Chapter 3: Literature Review explores the evidence-base for supported self-management. It presents information on the historical delivery of supported self-management programs. A synthesis of the international evidence for this interventional approach in cancer care is then provided. A critical appraisal of NZ and overseas evidence on supported self-management is presented. The Flinders Program was chosen as the supported self-management intervention to be studied based on the evidence.

Chapter 4: Phase one presents the rationale, methods, results and discussion of the qualitative modelling phase of the study framework. Focus groups were held with survivors. Key informant interviews were conducted with a selection of health and supportive care workers. Data from focus groups and interviews are synthesised and presented. The discussion section reviews considerations for progression to phase two of the study framework.

Chapter 5: Phase two presents the rationale, methods and results of the quantitative exploratory pilot study. The Flinders Program was administered to people completing active treatment for colorectal cancer in the hospital-based cancer treatment setting in NZ. Recruitment, data collection and intervention delivery processes are reviewed in this chapter. The results and analyses are described.

Chapter 6: Discussion summarises the research and integrates the findings to address the five research questions. Enablers and barriers to the intervention are discussed. Strengths and limitations of the framework are presented. Clinical and research implications for survivorship care and The Flinders Program intervention are identified. Recommendations to progress survivorship research are made.

Consultation and approvals

Both phases of the research studies were submitted concurrently for approval to specific advisory groups and ethics committees. In 2012, formal Māori consultation took place with Ngai Tahu and the Capital & Coast Research Advisory Group – Māori. Study approval was granted. In addition, the studies received approval from the Central Health & Disability Ethics Committee that same year (12/CEN/12). Locality assessment and approvals were also provided by Capital & Coast District Health Board. Approval was also obtained from the developers of The Flinders Program who are based at Flinders University in Adelaide, Australia.

A list of presentations delivered at international conferences based on the research described in this thesis can be found in the final appendix (Appendix 0). Also included is a reprint of an April 2016 survivorship overview article published in CanNet, a journal of the NZ Nurses Organisation. That article initiated discussions that has led to a national survivorship framework project currently underway in NZ. It is a joint project between the Cancer Society, the regional cancer networks and the Cancer Nurses College. The inaugural workshop was held on 2 November 2016. The information presented in this thesis is proving invaluable to progressing that project.

CHAPTER 2: Background

Cancer impacts on one in three New Zealanders (Ministry of Health 2016; Cancer Society of New Zealand 2016). It is the leading cause of morbidity and mortality in NZ (Ministry of Health 2015a; Tobias and Turley 2012). Interventions to address the life and health impacts of cancer on patients and survivors is the context for this thesis. This chapter presents background information on contemporary cancer care, cancer impacts and delivery of interventions.

Research into the high burden of cancer in NZ and the associated ethnic inequity have signalled the need for ongoing research and quality improvement in cancer care delivery (Ministry of Health and University of Otago 2010; Robson et al. 2005; Robson et al. 2010). The steadily increasing numbers of NZ cancer survivors (Soeberg et al. 2012) points to the need for more NZ-based research to address inequities and support survivors with managing the intermittent, yet often lingering, impacts of cancer.²

This background chapter is in three parts. Part one provides an overview of cancer in NZ with a focus on colorectal cancer. Part two explores survivors experiences and impacts of cancer as well as the role of The Chronic Care Model (Wagner et al. 1996). An overview of interventions is presented in part three with specific considerations identified for cancer survivorship. These three parts establish the foundation for this thesis on NZ cancer survivor experiences and the acceptability, feasibility and pilot delivery of a supported self-management intervention program as a component of survivorship care pathways. Overall, the key message of this chapter is that awareness of the 'work' of cancer survivorship and delivery of effective interventions as part of redesigned care pathways is multifaceted. Research into interventions cognisant of individual and environmental factors is needed.

² The studies described in this thesis focus on interventions for survivors of adult-onset cancers while recognising that childhood cancer survivors are also an important part of the cancer survivor community.

Part one: Cancer survival and cancer care trends

Cancer is a leading cause of sickness and death nationally in NZ (Ministry of Health 2015a). There were 21,050 cases of new cancers reported to the NZ Cancer Registry in 2011 (Ministry of Health 2015a). The most prevalent registered cancers in that year were breast, prostate and colorectal cancers (Ministry of Health 2015a). Attributed to an ageing population and increasing population, numbers of cancer diagnoses are on the rise in NZ, particularly among those 65 years of age and older (Tobias and Turley 2012; Ferlay et al. 2015). The ongoing impacts and burden of cancer on health and wellbeing are substantial for cancer survivors (Parkin et al. 2001; Ministry of Health and University of Otago 2010).

Colorectal cancers comprise the disease reference context for this work because these cancers are common in NZ (Ministry of Health 2015a; World Health Organization 2008) and there is an unequal burden on mortality by ethnicity (Robson et al. 2010). Further, research with colorectal cancer cohorts is underfunded considering relative disease burden (Carter and Nguyen 2012) and more research is needed to support cancer survivorship. Therefore, the focus for these studies is on addressing common impacts and complexities associated with colorectal cancer as well as intervention to help address these problems.

Cancer trends: Increasing survival and disparities

Cancer survival

Cancer survival is increasing in many Westernised countries due to earlier detection and more effective treatment options. Prior to the 1980's, the cancer trajectory was mostly linear and finite extending from symptoms, diagnosis, treatment, limited remission, recurrence and death (Aziz 2007). Research progress over the last half century has contributed to improvements that include earlier diagnoses and better treatment options (Levit et al. 2013). These improvements have resulted in long-term remission or cure for many of those diagnosed with cancer (Hewitt, Greenfield, and Stoval 2006). Data available from cancer management registries illustrate this trend. Figure 1 shows cancer survival trends in the USA (National Cancer Institute 2016) and Figure 2 shows these trends for the UK (Cancer Research UK 2014).

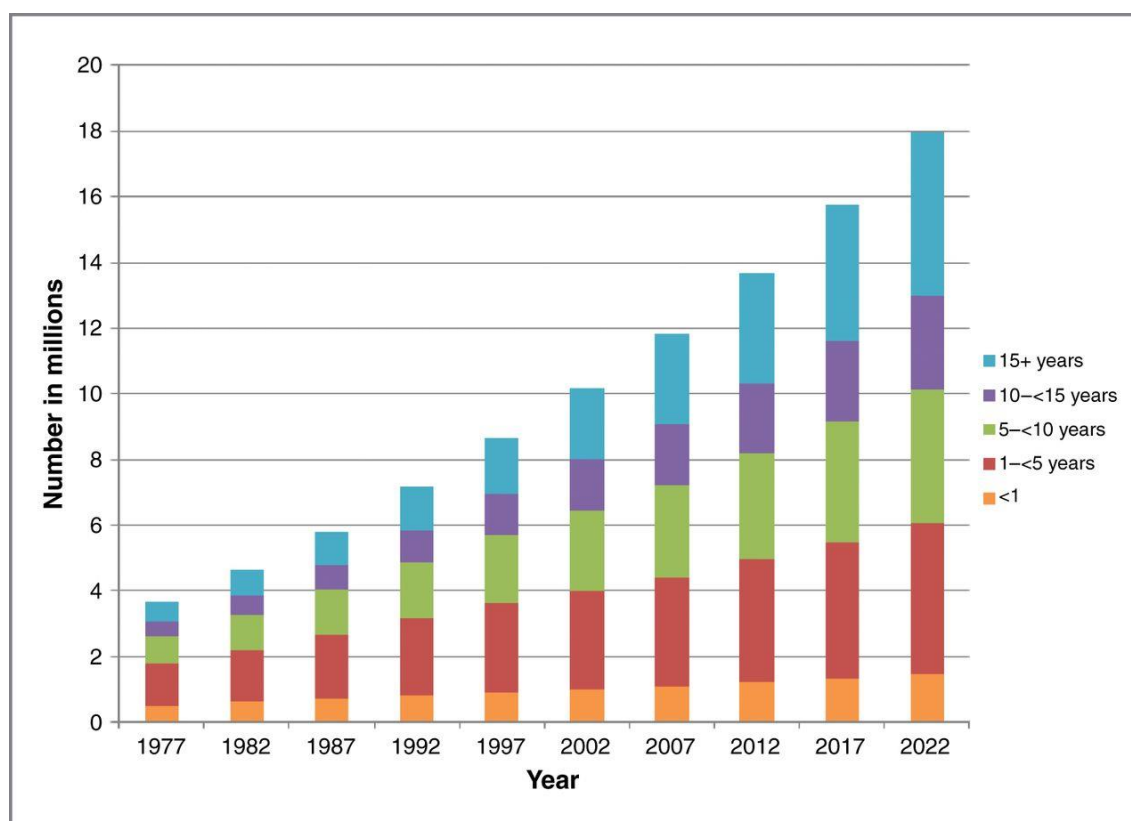


Figure 1: USA cancer survivor numbers and projections 1973 – 2024

Source: De Moor et al. 2013, 563

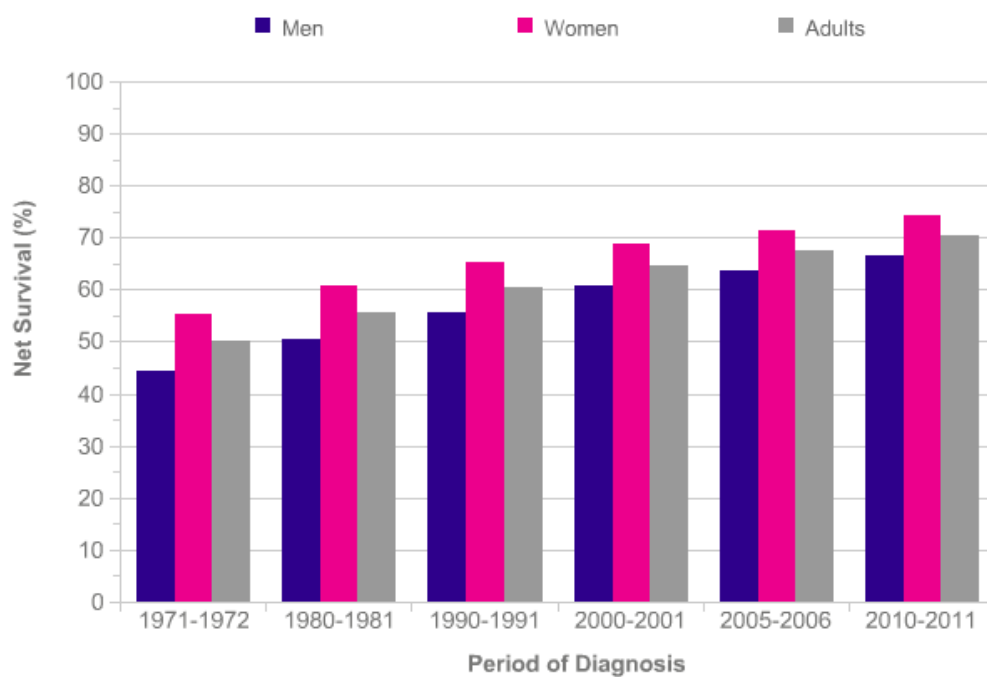
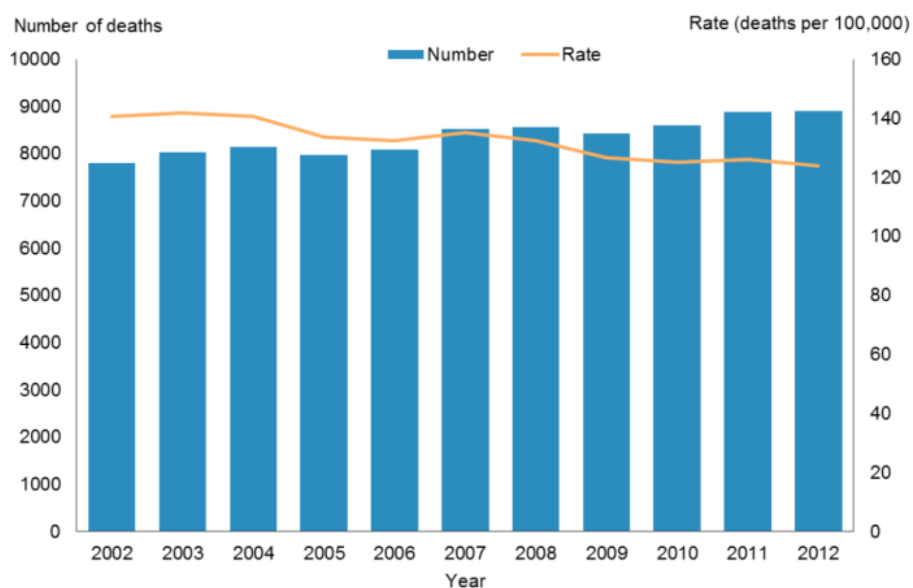


Figure 2: All cancers age-standardised one-year net survival, England and Wales, 1971-2011

Source: Cancer Research UK 2014, <http://www.cancerresearchuk.org/>

Rising numbers of cancer survivors in NZ are reflective of similar epidemiologic cancer trends as highlighted for the USA and the UK. Cancer Research UK states cancer survival has doubled in the last 40 years and that 50% of people diagnosed with cancer will now live, on average, ten or more years (Cancer Research UK 2014). In NZ, the 2012 Cancer Trends report was based on data from linked census and cancer data sets analysed for the years 1991 through 2004. Although survival rates were noted to vary by cancer site, ethnicity and socioeconomic group, the report documented an overall increased survival from cancer and a 3% annual improvement in cancer survival across 21 different cancers (Soeberg et al. 2012). Data showed that the overall cancer death rate in NZ fell by 32 percent (Soeberg et al. 2012). This declining cancer death rate is shown in Figure 3 which illustrates numbers of attributable cancer deaths for the years 2002 to 2012 (Ministry of Health 2015a). Figure 3 shows the number of deaths from cancer increasing during the decade, related to a growing population and an ageing demographic, but an overall decline in the cancer death rate (Ministry of Health 2015a). The correlate of a declining death rate is rising cancer survival.



Note: rates are expressed per 100,000 population and age-standardised to the WHO World Standard population.

Source: New Zealand Mortality Collection

Figure 3: Number of deaths and corresponding cancer survival rate over a 10-year time period in NZ, 2002-2012

More recent NZ Ministry of Health data points out a rise in numbers of cancer survivors (Ministry of Health 2015b). Data from a 2015 report showed five-year cumulative relative survival increased from 0.58 to 0.62 between 1998 and 2007. Data also showed 78% of New Zealanders diagnosed with cancer in 2010-11 survived over one-year relative to background mortality (Ministry of Health 2015b).

Cancer survivors are currently estimated to represent 32.5 million people globally (Koczwara 2015) and between three and four percent of the populations of the UK, Australia, NZ and the USA (Aye, Elwood, and Stevanovic 2014; Ministry of Health 2015b; Soeberg et al. 2012; Australian Institute of Health and Welfare 2012; Macmillan Cancer Support 2011; American Cancer Society 2015). The one-year, five-year and 10-year cancer survival rates in each of these countries has been projected to continue to rise over the coming years (Cancer Research UK 2014; National Cancer Institute 2016; Ministry of Health 2010a).

Inequities in cancer care and outcomes

A second global epidemiologic trend of importance is the persistence of disparities by age, income, ethnicity, geography and cancer site (Aziz 2007). It is clear that cancer is inequitably distributed between socioeconomic groups, ethnic groups, males and females and people living in different geographical areas of NZ (Minister of Health 2003b). Reducing inequities is a key principle that has consistently been noted in NZ government health strategies since 2000 (Minister of Health 2016a; Minister of Health 2003b; Dyson 2002; Ministry of Health 2002; King 2001).

Disparities have been documented in stage at diagnosis (Blakely et al. 2012; Byers et al. 2008; Priest et al. 2010), access to cancer treatment and psychosocial services (Alter 2009; Sarfati et al. 2009; Hill et al. 2010) and mortality (Byers et al. 2008; Cunningham et al. 2014; Hill et al. 2010; Shaw et al. 2006; Soeberg et al. 2012). The combined and concerted efforts of many overseas and NZ researchers have highlighted significant disparities in cancer incidence, mortality and care over the decades (Blakely et al. 2004; Cormack et al. 2005; Hill et al. 2013; Robson et al. 2005; Soeberg et al. 2012; Walker et al. 2008).

The reasons for disparities in health and inequitable access to care are complex. Disparities have been shown to be strongly associated with unequal distribution of the

determinants of health (Blas and Kurup 2010; Tobias and Turley 2012). Individual factors, such as lifestyle behaviours, also play a role (Minister of Health 2003b). The leading advisory body in the USA, the Institute of Medicine (IOM), recommends that interventions are developed and tested in specific populations that experience disparities (Adler and Page 2008; Alter 2009).

Māori are the indigenous people of NZ. They are inequitably impacted by cancer. Reducing inequities for Māori is a Treaty of Waitangi obligation addressed by numerous policy documents including the current NZ Health Strategy (Minister of Health 2016a) and Māori Health Strategy (Ministry of Health 2002). Addressing inequities is woven through NZ cancer-specific health strategies and action plans (Minister of Health 2003b; Cancer Control Taskforce 2005). Nevertheless, studies show continued disparities. One-year cancer survival for non-Māori remains approximately 10% higher than for Māori with a trend of steady increases across both groups (Ministry of Health 2015b). The Cancer Trends study utilised relative survival rates to quantify survival estimates and demonstrated persistent survival inequity affecting Māori and those from lower socioeconomic groups (Soeberg et al. 2012). Concerns have been highlighted in several studies that cancer care pathways in NZ contribute to inequitable access to care (Doolan-Noble et al. 2006; Doherty 2006; Waitemata DHB 2006; Hill et al. 2010). Equity is an important consideration for survivorship research.

The argument proposed in this thesis is that NZ cancer care pathways need to evolve to address epidemiologic trends such as those described in relation to survival and inequity. Early evolutionary changes are apparent with work progressing on comorbidities and cancer (Sarfati, Koczwara, and Jackson 2016; Stairmand et al. 2015), documenting discrepancies in decision-making in cancer care (Dew et al. 2015; Stairmand et al. 2015) and highlighting cancer patient experience (Dew et al. 2015; Egan et al. 2014; O'Brien et al. 2010; Slater et al. 2013; Walker et al. 2008). However, a gap in survivorship care persists and intervention research is needed to progress evidence-based survivorship approaches that are acceptable for Māori and standardised across NZ.

Cancer care in NZ: The cancer control continuum

Cancer survival is a measure of the effectiveness of cancer control measures (Ministry of Health 2015b). The NZ Cancer Control Strategy aims to impact on cancer control by outlining systematic and planned approaches that reduce the impact of cancer and reduce inequities across the cancer control continuum (Minister of Health 2003b). The cancer control continuum extends from prevention through diagnosis, treatment, rehabilitation and palliative care (Minister of Health 2003b).

The 2003 Cancer Control Strategy and 2005-2010 Action Plan did not include a survivorship component (Minister of Health 2003b; Cancer Control Taskforce 2005). Nowadays, survivorship is the contemporary term used when describing life and cancer care during and post-treatment (Hewitt, Greenfield, and Stoval 2006). It does not replace rehabilitation, but is an additional and integral part of the continuum. Because survivorship, is not included in the 2003 NZ Cancer Control Strategy, survivorship interventions may not be prioritised (Cancer Control Taskforce 2005). Therefore, consideration of redesigned care pathways that aim to “improve[e] the quality of care provided to cancer survivors [through delivery of] comprehensive, coordinated and tailored care” (Halpern et al. 2014, e19) may not be as well supported by existing NZ policy documents as warranted by the survivorship statistics.

Cancer care pathways: Survivorship shift and colorectal cancer

In this section, cancer care pathways from the point of diagnosis through survivorship are summarily described. The inclusion of a survivorship lens supports exploration of specific considerations not always associated with these stages. Examples of the expanded scope indicated by survivorship are identified.

Diagnosis

A definitive diagnosis of cancer often happens after a period of time that includes identification of signs and symptoms, assessment, tests, and confirmation (or elimination) of a cancer diagnosis (Minister of Health 2003b). Once a cancer diagnosis is confirmed, treating clinicians formulate treatment options. In NZ, these options are often discussed at multidisciplinary team meetings (Dew et al. 2015; Stairmand et al. 2015). Clinicians may

discuss options with patients leading up to decisions on a treatment plan (National Bowel Cancer Tumour Standards Working Group 2013).

A cancer diagnosis has been shown to be a common source of fear, anxiety and stress for the newly designated patient and their whānau (Adler and Page 2008). Cancer-related fear and anxiety are commonly experienced at the time of diagnosis (Little et al. 1998; Zabora et al. 2001; Naus, Price, and Peter 2005; O'Brien et al. 2010). These stressful feelings impact on individual decision-making ability (Dy and Purnell 2012; Stiggelbout et al. 2012). Those affected by cancer must decide who to tell and how to manage day-to-day amidst disruptions to usual routines (Levit et al. 2013). Research shows that the impact of a cancer diagnosis and treatment on the whānau is often as significant as that experienced by the individual survivor (Fitch, Bunston, and Elliot 1999; Giovannetti et al. 2012; Slater et al. 2013).

A cancer diagnosis contributes to life and health complexity for many people. Health complexity can be triggered or exacerbated by cancer (Schaink et al. 2012; Sarfati, Koczwara, and Jackson 2016). Health complexity models have been developed that incorporate socioeconomic, cultural, structural and other environmental factors that can affect care and outcomes (Safford, Kiefe, and Allison 2008; Schaink et al. 2012). People diagnosed with cancer report experiencing a flow on effect leading to marital, family, social and vocational role challenges (Levit et al. 2013; Hewitt, Greenfield, and Stoval 2006). The 2008 IOM report entitled *Cancer Care for the Whole Patient: Meeting Psychological Needs* recommends greater integration of psychosocial support services to address cancer-related complexity and impacts (Adler and Page 2008).

Colorectal cancers are the context used to illustrate diagnosis pathways in this thesis. People may be diagnosed with colorectal cancers through routine screening, symptomatic presentation to a primary care practice or emergency department, or via asymptomatic incidental detection (National Bowel Cancer Tumour Standards Working Group 2013).

Incidence and prevalence data on colorectal cancers are relevant in this context. Colorectal cancers affect people of all ages, genders and ethnicities in NZ (Ministry of Health 2015a). Colorectal cancer includes cancers of the large bowel, rectosigmoid junction and rectum (Ministry of Health 2015a). These cancers are the in the top three of most common cancer diagnoses in NZ (Ministry of Health 2015a) and internationally (IARC 2012; World Health Organization 2014). People who reside in NZ have among the highest incidence and mortality rates for colorectal cancer internationally (IARC 2012).

Colorectal cancer incidence rates are higher for men with greater prevalence amongst older age groups (Cunningham et al. 2009; Ministry of Health 2015a). Colorectal cancer incidence rates are up to twice as high for European/Other groupings than for Māori, Pacific and Asian peoples (Soeberg et al. 2012).

There are documented inequities in colorectal cancer incidence and mortality, as well as care, in NZ. For example, age standardised colorectal cancer incidence rates are lower for Māori compared to non-Māori, but mortality rates are similar (Ministry of Health 2015a). In other words, Māori are more likely to die once diagnosed. NZ data has shown that Māori are likely to have more advanced disease at the time of diagnosis and lower rates of access to health services (Cormack et al. 2005; Robson, Purdie, and Cormack 2010). These are just some of the differential trends and inequities in colorectal cancer incidence, mortality and care by ethnicity identified in the literature (Shaw et al. 2006).

One contributor to complexity that is common in colorectal cancer survivors is comorbidity (Sarfati et al. 2013). Comorbidity is defined as the presence of concurrent long-term health conditions and it is associated with poorer cancer survival and health outcomes (Sarfati, Koczwara, and Jackson 2016). Comorbidities can pre-exist a cancer diagnosis or develop during or post-treatment.³ A 2004 study conducted in the USA showed that cancer survivors often do not receive recommended care for concurrent health conditions with detrimental effect (Earle and Neville 2004). The study reported that “comorbid conditions are the major threat to life for many cancer survivors” (Earle and Neville 2004,1712) due to the potential to neglect care for other serious illnesses. Presence of comorbidity or other health complexity may impact on diagnosis and delivery, or uptake, of best-practice healthcare (Sarfati, Koczwara, and Jackson 2016; Schaink et al. 2012). The lifeworlds of cancer survivors are often characterised by comorbidity as well as socioeconomic, cultural and other life complexities that can impact on diagnosis and treatment decision making (Galvin and Todres 2013; Dew, Stubbe et al. 2015; Stairmand et al. 2015).

Comorbidity is common in NZ with chronic cardiovascular illness, metabolic illness or diabetes coexistent in a third to half of all adults diagnosed with cancer (Sarfati, Koczwara, and Jackson 2016). Specific to colorectal cancer, a 2009 independent audit of clinical notes in NZ found that two-thirds of colorectal cancer survivors were diagnosed with

³ Cancer-related conditions that develop and persist related to the cancer itself or during active treatment are called long-term effects while conditions that develop post-treatment as outgrowths from the effects of treatments on an organ system or psychological process are called late effects (Aziz 2007).

comorbidities including hypertension (35%), ischaemic heart disease (17%), and respiratory disease (16%) (Cunningham et al. 2009). Comorbidity has been found to impact on diagnosis and treatment in NZ (Stairmand et al. 2015; Sarfati et al. 2009). In Sarfati et al's 2016 overview of the impact of comorbidity on cancer and its treatments, the authors identified a gap in application of chronic care models to cancer survivor care and management. They recommend that “we need to move beyond the present single-disease model of studying cancer and embrace the complexities of studying and managing people with complex medical conditions” (Sarfati et al. 2016, 8). This translates to ensuring interventions aiming to improve survivorship care and outcomes consider health complexity as part of the landscape.

Treatment

In NZ, colorectal cancer treatment guidelines provide best-practice advice on treatment options. Recommended options usually involve combinations of surgery, cytotoxic agents or chemotherapy, biologically targeted agents or immunotherapy, and radiation therapy (New Zealand Guidelines Group 2011). The multidisciplinary team approach is a common feature of colorectal cancer treatment planning in NZ with discussions about individual patient management occurring between surgeons, medical and radiation oncologists, pathologists, radiologists, and clinical nurse specialists as members of a clinical team (Stairmand et al. 2015; Dew, Stubbe et al. 2015; National Bowel Cancer Tumour Standards Working Group 2013; New Zealand Guidelines Group 2011).

Clinical colorectal cancer management is supported by the *Standards of Service Provision for Bowel Cancer Patients in New Zealand - Provisional* (2013), previously published guidelines (NZ Guidelines Group, 2011) and guidance (Ministry of Health 2010b). These policies and standards for care “allow clinical regimens to be administered to best advantage” (Herrstedt and Walsh 2011, 335) increasing the possibility of achieving best-case treatment outcomes in terms of response rates and survival. Individuals and whānau seeking colorectal cancer treatment from a NZ healthcare facility are routinely managed through acute, disease-specific care pathways delivered by regional cancer treatment centres (Cancer Control New Zealand 2010). The focus of treatment is control of disease with the goal most commonly being ‘cure’. The cancer treatment phase of the cancer care trajectory lasts anywhere from a few days, for surgical removal of a tumour, to many years

with phases referred to as neoadjuvant or adjuvant first-line, second-line and subsequent modalities (National Bowel Cancer Tumour Standards Working Group 2013).

Surgical resection of the bowel is the most common treatment modality for people diagnosed with colorectal cancer in NZ (Cunningham et al. 2009; New Zealand Guidelines Group 2011). A section of bowel that contains the tumour is cut out along with margins of healthy bowel. The resulting bowel segments may be either re-connected or a stoma formed from attaching the proximal end of the bowel to the surface of the abdomen. Individuals with some forms of colorectal tumours (i.e. rectal cancers) and for cases presenting with metastatic disease, surgery may be preceded by neoadjuvant radiotherapy and chemotherapy to shrink the size of the tumour and enable secondary review of surgical treatment options.

Colorectal cancers are staged, according to tumour aggressiveness and spread, at the time of surgical removal of the tumour (National Bowel Cancer Tumour Standards Working Group 2013). The TNM disease staging system, as maintained by the American Joint Committee on Cancer and the International Union for Cancer Control, is considered the strongest predictor of survival (International Union for Cancer Control 2007). Prognosis is usually good for treated local (stage I) and regional (stage II) colorectal cancers. Further treatment, with adjuvant chemotherapy, is thought to reduce the likelihood of recurrence for cancers that have spread or metastasised to regional lymph nodes (stage III) or distant lymph nodes (stage IV). Adjuvant chemotherapy is likely to be recommended if pathological evidence obtained at surgery indicates that the cancer may have spread to regional lymph nodes. Post-surgical adjuvant chemotherapy for stage III and IV tumours often begins within eight weeks post-surgery. Stage IV describes a tumour that has spread to sites distal to the bowel or rectum as identified by abdominal ultrasound, computerised tomography or magnetic resonance imaging. Treating clinicians may use targeted therapies but this stage designation carries with it a poor prognosis. The liver and lungs are the most frequent sites for distant metastases or recurrent disease. Relative survival rates differ by stage at diagnosis with better colorectal cancer survival rates associated with stage I and II cancers. In NZ, approximately 60% of cancer survivors reach the five year survival milestone (Aye, Elwood, and Stevanovic 2014).

Best-practice guidelines refer to delivery of evidence-based clinical and supportive care services for cancer patients (Ministry of Health 2010b; National Bowel Cancer Tumour Standards Working Group 2013). Supportive care is an approach to address the holistic

aspects of cancer care (Ministry of Health 2010b). It includes “essential services required to meet a person’s physical, social, cultural, emotional, nutritional, information, spiritual and practical needs through their experience with cancer” (Ministry of Health, 2010, p. 3). These services aim to improve the quality of life for those with cancer and whānau during diagnosis and treatment. The NZ Cancer Control Strategy (Minister of Health 2003b) states that provision of supportive care is a key component of high-quality cancer treatment. In 2010, the NZ Ministry of Health published supportive care guidance for health and supportive care workers (Ministry of Health 2010b). An implementation plan for the NZ Supportive Care Guidance identified three priority areas of focus for supportive care delivery: care coordination, psychosocial support and information support (Health Outcomes International 2011). As a result, NZ cancer services provided by district health boards (DHBs) routinely include care coordination. Cancer care coordinators and key support workers aim to integrate supportive care into the care continuum (Li et al. 2013; Collinson et al. 2013). Additional psychosocial and information support, for example counselling and support groups, are routinely available from community providers (Cancer Society of NZ, 2016). However, in reality, supportive care assessment is not routinely provided and access to supportive care is variable, services are inconsistently provided and programs rarely evaluated (Cancer Society of New Zealand and NZ Guidelines Group, 2006). There is a lack of evidence for cancer-specific supportive care service provision (Standard 14 of the *Standards of Service Provision for Bowel Cancer Patients in New Zealand - Provisional* (2013), which is likely to hinder delivery of these aspects of cancer care (National Bowel Cancer Tumour Standards Working Group 2013). In summary, the situation in NZ reflects that portrayed in the IOM report *Cancer Care for the Whole Patient: Meeting Psychological Needs*, which states “the remarkable advances in biomedical care for cancer have not been matched by achievements in providing high-quality care for the psychological and social effects of cancer” (Adler and Page 2008, 23).

Survivorship

The most internationally accepted definition of cancer survivorship is the one proposed by the National Coalition for Cancer Survivorship which reads “the experience of living with, through and beyond a diagnosis of cancer” (Hewitt, Greenfield, and Stoval 2006). This thesis adopts the following definition for the term ‘cancer survivor’.

An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends and caregivers are also impacted by the survivorship experience and are therefore included in this definition (National Cancer Institute 2015, 1).

The definition of cancer survivorship is not universally accepted in NZ. Many health practitioners and publications use this terminology to refer to the time after completion of active treatment due to clinical vagaries and prevailing paradigms (Hewitt, Greenfield, and Stoval 2006; Halpern et al. 2014). The American Society for Clinical Oncology (ASCO) rises above the terminology debate by acknowledging the term survivorship “means different things to different people but it refers to the process of living with, through or beyond cancer” (ASCO 2014, 4).

There are well-documented issues with survivorship terminology referred to in the literature (American Society for Clinical Oncology, 2014; de Silva and Health Foundation 2011; Hewitt, Greenfield, and Stoval 2006; Jefford et al. 2015). The term ‘survivor’ relates to being a victim for some (Hewitt, Greenfield, and Stoval 2006). Alternative terms for survivor suggested or in use include ‘people living with or beyond a history of cancer’, ‘people affected by cancer’, ‘consumers’ or ‘thrivers’ (Hewitt, Greenfield, and Stoval 2006; Macmillan Cancer Support 2011). The debate over terminology presents a barrier to progressing research in this area. The thesis acknowledges this debate and the difficulties it presents in achieving clarity, but rises above it by identifying the definition adopted in this thesis and progressing survivorship research despite it.

Prior to the 1980’s, a cancer diagnosis was likely to result in aggressive treatment, with little recognition of side effects that impacted on quality of life, followed by palliative treatment and untimely death (Miller, Merry, and Miller 2008; Ganz, Casillas, and Hahn 2008). Dr Fitzhugh Mullan was one of the first of a new breed of long-term cancer survivors. He coined the term ‘cancer survivor’ in his ground-breaking 1985 *New England Journal of Medicine* article, entitled ‘The Seasons of Survival’ (Mullan 1985). He pointed out the need for advocacy for those living with and beyond cancer to address unmet needs over three time periods which he coined as seasons. He called these seasons of survival: acute survivorship, extended survivorship and permanent survivorship (Mullan 1985). He described the category of acute survival as beginning at diagnosis and extending through primary treatment when fear and anxiety were constant and heightened. Extended survival began at the end of primary treatment when fear of recurrence and recovery from treatment-related physical limitations took place amidst periodic follow-up appointments.

Mullan's permanent survival season encompassed the five-year survival mark indicating "cure" but often with ever-present secondary impacts on mental and physical health.

Since Mullan's 1985 article, cancer has become increasingly survivable. This has heralded a new paradigm in cancer care based on consideration of cancer as a treatable chronic disease represented by an extended cancer trajectory. The National Cancer Survivorship Initiative from the UK outlined this pathway as seen in Figure 4.

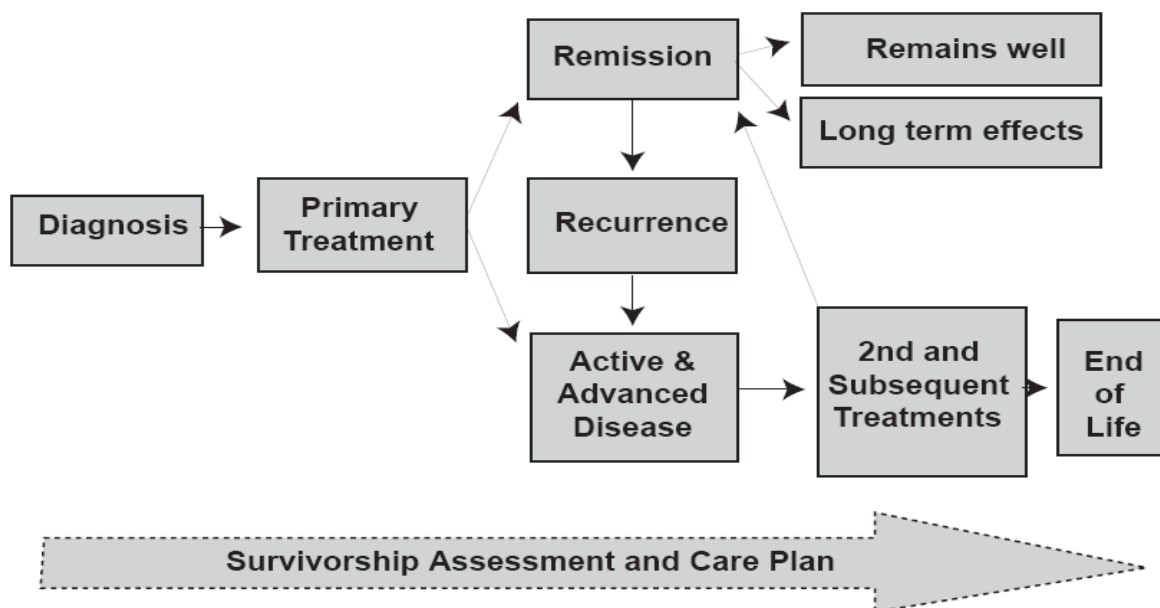


Figure 4: National Cancer Survivorship Initiative Vision, UK 2010

In 2007, Aziz published a review of the state of knowledge from cancer survivorship research studies (Aziz 2007). Cancer survivorship, as a discipline, was described as focusing on identifying and meeting the needs of people affected by cancer and its treatments (Halpern et al. 2014). Aziz's article highlighted the advances in cancer survivorship research from 1985. It documented that long-term impacts were previously considered less important than successful treatment outcomes (Aziz 2007). Aziz's article also outlined contemporary challenges and opportunities. The overview outlined the need for interdisciplinary approaches that:

1. Seek to identify, examine, prevent and control adverse sequelae of cancer and its treatments, such as fatigue and sexual dysfunction;
2. Manage, treat and prevent comorbidities;
3. Incorporate health promotion and lifestyle interventions to optimise health after cancer treatment;

4. Pay special attention to disparities in survivorship outcomes by age, income, ethnicity, geography or cancer site; and,
5. Explore the impact of the survivorship experience on the family and vice versa (Aziz 2007, 419).

Cancer survivorship is contemporarily characterised by a wide array of cancer-related impacts reported by cancer survivors. Research shows that survivors experience and manage ongoing life and health complexity during and post-treatment (Sarfati et al. 2009; Hewitt, Greenfield, and Stoval 2006; Aziz 2007; Eakin, Youlden, and Baade 2007; Ministry of Health 2015b; Koczwara 2015). As survivor advocacy and survivorship research progresses, so does the understanding of survivor seasons. Accordingly, Mullan's (1985) original stages of survivorship have been variously re-framed due to recognised variation in cancer-related impacts, survival rates and unmet needs for different cancers and population groups. Miller et al. (2008) revisited the seasons and expanded them to nine categories called: acute survivorship, transitional survivorship, three categories of extended survivorship and four categories of permanent survivorship.

Transitional survivorship, when treatment finishes and post-treatment survivorship work begins, is now recognised as a particularly vulnerable time of change for survivors (Miller, Merry, and Miller 2008). Transition is a particularly difficult period of the cancer trajectory for survivors to manage because confidence in health and life management has been knocked and needs to be rebuilt (Hewitt, Greenfield, and Stoval 2006; Zapka et al. 2012; Mannix-McNamara 2012; Foster and Fenlon 2011). The individual cancer experience, more often than not, includes transitional and extended survivorship phases, however, this cancer trajectory change has not been well documented in NZ. Further, care pathways have not evolved accordingly.

Rehabilitation is sometimes seen as synonymous with survivorship. Rehabilitation is defined as services to achieve optimal functioning across the domains of impairment, activity and participation (WHO 2001). As is the case for supportive care, there is variable access to rehabilitation services in NZ (Minister of Health 2003b). For example, rehabilitation may be provided post-surgery, while a patient is recovering as an inpatient, but not offered for physical impairment related to outpatient chemotherapy or radiation treatment. Rehabilitation is considered a component of cancer support in published NZ reports (Cancer Society of NZ and NZ Guidelines Group 2006; Ministry of Health 2003a) but there is a paucity of research that has addressed cancer rehabilitation in NZ

specifically (Cancer Society of NZ and NZ Guidelines Group 2006; Ministry of Health 2003b).

There is evidence from chronic care and long term condition research that support can help people improve their quality of life and feel empowered to better manage their own health (Foster and Fenlon 2011; Bodenheimer, McGregor and Sharifi 2005).

Recommendations from international survivorship studies have indicated the need for more research. It is clear that the healthcare delivery system and settings influence the capabilities and opportunities for survivorship models and care provision. More survivorship research is needed incorporating structural approaches in parallel with developments for intervention in other disease settings (Parkhurst 2013).

Survivorship research aims to find ways to address multi-faceted life and health complexities faced by survivors. A 2011 UK scoping review on the priorities for survivorship research concluded that research was needed in non-breast cancer survivor cohorts, on later phases of survivorship, and in rehabilitation and self-management approaches (Richardson et al. 2011).

Demonstration projects and survivorship interventions have taken place in many overseas cancer centres of excellence, community settings, and within the UK and Australia's national health systems (Oeffinger et al. 2014). Key agencies involved in survivorship research and advocacy are the National Coalition for Cancer Survivorship (USA), the LIVESTRONG Foundation (USA), MacMillan Cancer Support (UK) and The Australian Cancer Survivorship Centre at the Peter MacCallum Cancer Centre, in Melbourne, Australia. Koczwara specifically identified differing challenges and tensions in Australia associated with managing cancer survivorship in oncology versus the primary care environment (Koczwara 2015). Survivorship intervention settings have varied with no one setting identified as ideal.

Survivorship research studies have been carried out with cancer site-specific and survivorship-stage specific populations. Projects have been described as physician-led, nurse-led, and community-led (Dy and Purnell 2012; Halpern et al. 2014; Jefford et al. 2015). These projects have included numerous components. Two of the most common components were the survivorship care plan (Grunfeld et al. 2011; Klemanski, Browning, and Kue 2016) and shared care approach (Aziz 2007; Jefford et al. 2015; Landon, Grumbach, and Wallace 2012; Oeffinger et al. 2014).

Survivorship studies have utilised alternate approaches, such as counselling (Halpern et al. 2014) and risk stratification of survivors based on complexity and likelihood of late effects (Aziz 2007). Survivorship research to date has shown promise for redesigned care pathways incorporating these approaches or other tailored interventions to help survivors better manage challenges to their physical health, finances, relationships, emotions, identity and future prospects (Jefford et al. 2008; Kelly and Millward, 2004; Little et al. 1998; McCaughan et al. 2011; Walton et al. 2009; Watson, Mooney, and Peterson 2009).

Survivorship demonstration projects, meta-analyses and systematic reviews have not provided conclusive evidence regarding how best to meet the needs of survivors or deliver best-practice survivorship care (Halpern et al. 2014; Viswanathan et al. 2014; Koczwara 2015). The 2014 Agency for Health Care Quality and Research technical brief on existing models of survivorship care concluded:

The optimal nature, timing, intensity, format, and outcome of survivorship care models continue to be uncertain. The paucity of evidence limits our ability to make conclusions about the effectiveness of survivorship care models. Further research regarding survivorship care models, focusing on issues including settings, processes and continuity of care, payments, types of health care providers involved, collaborations and communications, outcomes and differences associated with cancer type or patient sociodemographic characteristics is needed before recommendations and conclusions regarding model development, implementation and evaluation can be made (Viswanathan et al. 2014, viii).

Four specific survivorship initiatives from NZ were identified in the grey literature:

Consumer advocacy, the Bridge to Health program (Cancer Society Otago/Southland Division 2015), as well as the Living Well and Kia Ora - E te iwi programs (Doherty and Borrell 2013). One additional on-line resource was identified.

NZ cancer survivors have played a role in increasing the awareness of cancer survivorship challenges and encouraging redesign of care pathways to reflect the contemporary cancer trajectory. The cancer survivors group, Cancer Voices NZ, was established in 2004 (Cancer Voices NZ Charitable Trust, 2016). Cancer Voices NZ aimed to address the first recommendation of the seminal cancer survivorship book *From Cancer Patient to Cancer Survivor: Lost in Transition* which is to “raise awareness of the needs of cancer survivors, and establish cancer survivorship as a unique phase of cancer care” (Hewitt, Greenfield, and Stoval 2006, 2). Although the group is no longer active, previous members of Cancer Voices NZ have been trained as patient advocates (Cancer Voices NZ Charitable Trust 2016). These survivor advocates continue to represent the consumer voice on regional and national advisory groups (Health Quality and Safety Commission 2015). Input from the

growing numbers of survivor patient advocates and consumer groups, on health policies and programs, has contributed to a growing awareness of the need for a dedicated survivorship focus in healthcare, research and policy arenas (Koczwara 2015). NZ cancer survivors now live for many years with impacts that range from physical to psychosocial, they are a growing advocacy voice, and their numbers are predicted to rise substantially in future decades (Ministry of Health 2015a; Soeberg et al. 2012).

Bridge to Health is a cancer survivorship program that was developed in Dunedin by Dr Sue Walthert of Otago University. Dr Walthert, a breast cancer survivor and GP, created the program to address the reported gap in community-based cancer survivorship support. The Otago/Southland Division of the Cancer Society delivers the Bridge to Health program for those who opt-in to join. The program aims to provide survivorship support and encourage the primary care provider-patient relationship (Cancer Society Otago/Southland Division 2015). It involves an initial two-hour education seminar followed by four workshops. The workshop topics address physical activity and personal fitness, nutrition, relationships and sexuality, and emotional wellbeing. Three vouchers for free GP visits are provided to participants at the completion of the program to encourage follow-up care. A 2012 evaluation report was referenced on the website but was not available for perusal. The report was described as documenting development, implementation and audit of the program. It indicated that the program met participants' needs and was useful (Cancer Society Otago/Southland Division 2015).

The Living Well and Kia Ora E Te Iwi cancer support programs are also group-based educational support programs. The Living Well Program was originally developed in the 1980's by the Cancer Council Victoria, Australia and later purchased by the Cancer Society of NZ. These programs were intended to be delivered as 'once a week for six weeks sessions facilitated by trained staff and guided structurally and educationally by delivery manuals. Program delivery models have been adapted. No review report of Living Well was available in the public domain. Kia Ora E Te Iwi is a kaupapa Māori adaptation the Living Well Program. The original and adapted programs have been administered over the years using alternative delivery models such as weekend courses, monthly meetings or a winter lecture series. The aims of these programs are to help people with cancer and their caregivers or whānau increase knowledge, confidence and coping skills (Doherty and Borrell 2013). The 2013 Kia Ora E Te Iwi review report described program implementation and views of key stakeholders (Doherty and Borrell 2013). The review did not aim to evaluate the effectiveness of programs, but recommended next steps on the basis of key

informant interviews. Key informants reported delivery to be challenging but identified Kia Ora E Te Iwi program development as an example of successful Kaupapa Māori intervention that has been delivered under the philosophy of Whānau Ora.

Recommendations for the future included identifying sustainable funding for programs, development of an ongoing reporting and monitoring system, and more training support for facilitators (Doherty and Borrell 2013).

The Nelson Regional Breast & Gynaecological Trust offer a link to a *Survivorship Passport* written by local cancer survivor activist, Andrea Fairbairn. This 31-page resource contains practical tips that women and their supporters can 'pick 'n mix' to a) manage health and recovery, and b) celebrate life (Fairbairn 2011). There was no evaluation report identified for this resource.

With regard to colorectal cancer survivor care pathways, there were no specific resources identified. Colorectal cancer survivors experience mid- and long-term consequences from the disease and its treatment (Hewitt, Greenfield, and Stoval 2006). Hewitt et al. (2006) described the late effects associated with colorectal cancer and its treatments as: 1) 40% risk of cancer recurrence; 2) increased risk of a secondary primary cancer; 3) higher rates of psychosocial distress; 4) bowel dysfunction; 5) colostomy; 6) sexual dysfunction; and, 7) peripheral neuropathy. Life for colorectal cancer survivors is often characterised by lingering impacts on wellbeing and health (Ohlsson-Nevo et al. 2012; Baravelli et al. 2009; Jones et al. 2016).

Sarfati et al. (2009) and Hill et al. (2010) identified the significant impact of comorbidities on colorectal cancer management and survival in NZ. As discussed earlier, they reported that the majority of people diagnosed with colorectal cancer are older and that they tend to have competing chronic diseases to manage, such as hypertension, diabetes, obesity, asthma, and/or frailty (Sarfati et al. 2009). Comorbidities have been found to alter treatment options offered to those affected (Sarfati et al. 2009; Hill et al. 2010). The physical and psychosocial post-treatment impacts associated with cancer can become, in themselves, comorbidities as these impact on health and wellbeing long-past the end of treatment.

In summary, people affected by colorectal cancer have their cancer treatment managed mainly within the hospital system but their additional health and life challenges may not be well supported. On completion of colorectal cancer treatment and rehabilitation, NZ patients often receive a discharge letter, a copy which is also sent to their primary care

provider and any other referring doctor. Further follow up occurs at intervals determined by the different treatment modalities involved in the care continuum. However, much of post-treatment care for treatment side-effects is provided by the care pathway readily available to survivors; namely, primary care providers. A wide variety of alternative survivorship care pathways have been studied overseas, but gold standard survivorship care remains elusive. Survivorship research and support can be initiated early in survivorship (i.e. during active treatment) or at transition from treatment or post-treatment.

Part one summary

The research presented in part one of this background chapter has provided a brief overview of the cancer trajectory from diagnosis through treatment whilst incorporating the concepts of survivorship. The standard NZ cancer journey is described as consisting of overlapping stages: diagnosis, treatment and survivorship. Each stage was described in relation to colorectal cancer as the context of interest.

Research shows that there are increasing numbers of cancer survivors and survivorship research is needed. This part one background chapter summarised cancer care pathways; from diagnosis through post-treatment. Key foundational researchers in the context of interest were identified to be NZ-based Professor Diana Sarfati (Sarfati et al. 2009; Shaw et al. 2006; Hill et al. 2010) and Australia-based Associate Professor Michael Jefford (Jefford et al. 2008, 2011, 2013, 2015). This background section provided background data and insights on cancer survival and cancer trends that emphasised the NZ perspective and colorectal cancer context.

Part two: Survivorship impacts and models of care

In this second part of the chapter, an overview of cancer impacts experienced by survivors, a framework of cancer survivorship work, and two applicable models of care are presented. Models of care shape services. They can guide how interventions can be effectively incorporated into service delivery. Cancer survivorship impacts are categorised as social, physical, emotional and spiritual which align with the Te Whare Tapa Whā model (Durie 1994). The work of cancer survivorship in managing these impacts is described using the Adapted Illness Trajectory Framework (Klimmek and Wenzel 2012) which is grounded in The Chronic Care Model (Wagner et al. 1996).

Survivorship impacts

Research shows that survivors navigate a range of impacts and transition points (Hubbard, Kidd, and Kearney 2010). It is recognised that there are substantial differences in survivorship impact due to differing cancer types, treatments, perceptions and experiences (Soeberg et al. 2012). Navigation of these cancer-related impacts often continues long-past the end of treatment with lingering effects. The Te Whare Tapa Whā model (Durie 1994) can be used to categorise causes and impacts of cancer across four areas: social, physical, emotional and spiritual. Survivors in NZ report coming to terms with their cancer experiences in various ways that alter their identity, life story and life-worlds (Egan et al. 2014).

Colorectal cancer survivor specific studies have been conducted overseas. In Australia, a 2008 report identified that dealing with fatigue, treatment transition, fear of recurrence, and unrealistic personal expectations were the most problematic challenges for colorectal cancer survivors in one Australian study (Jefford et al. 2008). Other challenges reported were managing ongoing post-treatment pain and gastrointestinal impacts as well as trying to carry out clinical advice on diet and physical activity (Jefford et al. 2008). In NZ, cancer survivor experience studies have been conducted including colorectal cancer survivors (Egan et al. 2014) but there have been no studies specifically focused on intervention for this group of survivors. This represents a gap that can be addressed through further NZ-based research.

Social impacts

Cancer impacts on survivors' sense of normality, sense of identity and self-confidence (Charmaz 2002; Hubbard et al. 2010). Social impacts of diagnosis and treatment have been reported in the literature (Dowswell et al. 2011; Pan et al. 2011; Ohlsson-Nevo et al. 2012; Anderson, Steele, and Coyle 2013; Dunn et al. 2013; Denlinger and Barsevick 2009). Social isolation is cited as a common occurrence noted to occur in survivors (Charmaz 2002) with intermittent disruptions to communication and relationships reported (Zhang and Siminoff 2003).

Cancer as a chronic illness is characterised by biographical disruption (Bury 1982). Cancer has been described as disruptive to both daily life and a planned future (Hubbard, Kidd, and Kearney 2010). Disrupted daily life and future plans leave survivors feeling frightened and anxious; aware that they are not living up to societal norms, and with a fragile and constantly altering sense of self and identity (Naus et al. 2009; Hubbard, Kidd, and Kearney 2010). New meanings were needed to guide survivors' future goals and decision-making (Cardoza 2016; Kantor 2016).

Unresolved social impacts were reported to be exacerbated by practical difficulties with work and travel (Mehnert 2011; Lobb et al. 2009). Both men and women reported changes in employment during cancer treatment (Mehnert 2011; Lobb et al. 2009; Richardson et al. 2011). For those unable or unwilling to return to work, social isolation was exacerbated by financial stress (Mehnert 2011). One research study from Holland found that 62% of working age survivors returned to work following cancer treatment (Spelten, Sprangers, and Verbeek 2002). However, the cancer experience affected their perception of work. Cancer-related identity changes were associated changed attitudes toward work (Kennedy et al. 2007). One study described the difficulties experienced by male survivors who reported a burdensome shift in identity from hard-worker and authoritative father to perceived weak man (Elmberger, Bolund, and Lützén 2002). In another study, female survivors reported anxiety and internal struggles associated with not being able to meet family needs (Fitch, Bunston, and Elliot 1999). Seemingly, people do not want illness dominating their lives and they seek a sense of past normality. However, work and home roles are often affected by a cancer diagnosis and this results in impacts on self-esteem, identity and priorities (Galvin and Todres 2013; Hubbard, Kidd, and Kearney 2010; Fitch, Bunston, and Elliot 1999; Elmberger, Bolund, and Lützén 2002).

Physical impacts

The most common physical impacts associated with cancer treatments in the literature were fatigue, pain and gastrointestinal symptoms. Definitions for these symptoms were sourced from the National Comprehensive Cancer Network (NCCN) guidelines. The NCCN guidelines provide clinicians with strategies for management of cancer-related symptoms including recommendations for ongoing assessment, education, pharmacologic treatments, physical activity, and counselling and other psychosocial interventions.

The NCCN defines cancer-related fatigue as a “persistent, subjective sense of tiredness related to cancer and cancer treatment that interferes with usual functioning” (National Comprehensive Cancer Network 2014b). In one cross-sectional national survey of American cancer survivors, cancer-related fatigue rates were reported to be high with 80% of people receiving chemotherapy and 90% of people receiving radiotherapy reporting this symptom at intervals during treatment (Henry et al. 2008; Hofman et al. 2007). Overall, cancer-related fatigue impacted on between 50-90% of people living with, through and beyond cancer with this symptom known to be both a cancer indicator and a side-effect of treatment that can persist long beyond treatment for many survivors (Hofman et al. 2007; Campos et al. 2011; National Comprehensive Cancer Network 2014b; Jones et al. 2016).

The NCCN defines cancer pain as “an unpleasant, multidimensional, sensory, and emotional experience associated with actual or potential tissue damage, or described in relation to such damage” (National Comprehensive Cancer Network 2014a). Cancer pain can result from tumour pressure on tissues, nerves and bone or disruption in organ function (Cardoza 2016). It also can be associated with treatment and associated procedures, particularly those that require the use of needles. Pain is known to be a common yet variable physical impact that can evolve into a chronic pain syndrome for survivors (Cardoza 2016).

Gastrointestinal symptoms impacting across all cancers include changes in taste, nausea, vomiting, constipation or diarrhoea (Cardoza 2016). Many treatments impact on the cells of taste buds and those that line the gastrointestinal tract which triggers these symptoms. The NCCN has antiemesis guidelines that assist clinicians with strategies for pharmacologic and non-pharmacologic management of gastrointestinal conditions (National Comprehensive Cancer Network 2012). Specifically referring to colorectal cancer

survivors, research has identified post-operative stoma and ostomy device management as an ongoing challenge (Pan and Tsai 2012; Kidd et al. 2008; Baravelli et al. 2009).

Additional side-effects known to impede recovery of increased functional ability include lymphatic system disruption resulting in painful swelling called lymphoedema (Hewitt, Greenfield, and Stoval 2006), cognitive impairment (Levit et al. 2013), sexual dysfunction (Dowswell et al. 2011) and endocrine dysfunction (Aziz 2007; Eiser et al. 2007).

Emotional impacts

Emotional health can be affected throughout the cancer trajectory. Common psychological impacts identified from the literature include distress, depression and anxiety (Mulrooney, Neglia, and Hudson 2008). The emotional impact most often described in conjunction with cancer treatment is 'distress' (Hewitt, Greenfield, and Stoval 2006; Kantor 2016). Distress is described as a negative emotional reaction to uncertainty and fear about outcomes or death (Zabora et al. 2001). Other common emotional impacts associated with cancer are the more specific diagnoses of depression and anxiety.

The NCCN defines distress as a “multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment” (National Comprehensive Cancer Network, Holland, and Bultz 2007). Distress experiences range from feelings of sadness and vulnerability to depression, anxiety and panic (National Comprehensive Cancer Network 2013). Psychological distress levels fluctuate but it has been reported to be experienced by 35% or more of people undergoing cancer treatment (Zabora et al. 2001). A large scale prospective study of colorectal cancer survivors found that “a substantial proportion of participants reported high levels of distress, with one-third still distressed five years post-diagnosis” (Dunn et al. 2013, 1763).

Specific disorders such as depression and anxiety are identified in survivors. Depression, defined as persistent low mood, has been identified in 16% of cancer patients (Osborn, Demoncada, and Feuerstein 2006). Research suggests anxiety is a more prevalent problem during survivorship (Kantor 2016). Fear of recurrence is one common and recurrent form of illness-related anxiety in survivors that can manifest as hypochondria or avoidance behaviours (Lobb et al. 2009; Denlinger and Barsevick 2009). Prescriptions for

psychotropic drugs used to treat depression and anxiety are more commonly written for survivors compared to the general public (Ng et al. 2013).

Some researchers have proposed that illness-related anxiety can have positive outcomes. Tedeschi and Calhoun introduced the concept of post-traumatic growth in 2004 (Tedeschi and Calhoun 2004). This concept describes a process of positive change after a life-altering event that can result in “an increased appreciation for life in general, more meaningful interpersonal relationships, an increased sense of personal strength, changed priorities, and a richer existential and spiritual life” (Tedeschi and Calhoun 2004, 38).

Spiritual impacts

Spirituality has several working definitions. It is defined in both purely religious terms and in broader terms relating to meaning, purpose and values in life (Egan 2009). This thesis adopts Puchalski’s definition which states that spirituality is “the way people find meaning and purpose, and how they experience their connectedness to self, others, the significant, or sacred” (Puchalski 2012, iii49).

Spiritual impacts were comprehensively described in Egan’s 2009 national study of spirituality toward the end of life (Egan 2009). Egan highlighted the significant differences in definition, perceptions and experiences of spirituality held by NZ peoples. For Māori, spirituality was described as an integral part of cultural identity and wairua (Egan 2009). Wairua is one of the four cornerstones of Durie’s Te Whare Tapa Whā Māori health philosophy (Durie 1994). A quote from a different study illustrates the importance of spirituality for one Māori female.

Spiritual is Māori. Māori as a culture are a spiritual people ...that does not mean that we are god fearing people, I am a spiritual person not a church person (Whitehead 2010).

Spiritual impacts identified in the cancer-specific literature include existential concerns, such as lack of meaning in life or worries about the afterlife, feelings of grief and loss, guilt and shame, or concerns about reconciliation with the past (Puchalski 2012). A sense of spiritual abandonment, sometimes indicated by a person describing perceived lack of love in their life or anger at God, has been described as a factor contributing to spiritual distress (Puchalski 2012).

Spiritual distress can be assessed and addressed in many ways, not solely through delivery of spiritual care. Spiritual care has been found to improve survivors' quality of life and satisfaction with care (Puchalski 2012). The UK National Institute for Clinical Excellence guidance for supportive and palliative care recommends that spiritual care include "informal sharing of ideas about the ultimate purpose of existence" (National Institute for Clinical Excellence 2004, 96). Spirituality is a pathway for survivors to reframe their identity in the context of cancer, find greater meaning in life, and recognise what is ultimately of importance and value to them (Egan 2009).

Addressing cancer impacts as chronic

Cancer is defined as a chronic condition by the World Health Organization (World Health Organization 2008) and the IOM (Hewitt, Greenfield, and Stoval 2006). In NZ, chronic care and long-term condition terminology are used interchangeably. A long-term condition refers to "any ongoing or recurring health issue that has a significant impact on the lives of a person and/or their family, whānau or other carers for six months or more" (Bycroft and Boyd 2011, 11).

A parallel can be drawn between the illness experiences of people living with chronic conditions such as asthma, diabetes and arthritis, and cancer survivors (Lancet 2012; National Health Committee 2007b; Schoen et al. 2009; Michie, Miles, and Weinman 2003). A diagnosis of cancer or other chronic condition impacts on physical and psychosocial health (Tritter and Calnan 2002; Hubbard, Kidd, and Kearney 2010; Lancet 2012). These illness experiences can be disabling, painful, embarrassing and stigmatizing (Tritter and Calnan 2002). There is an impact on perceptions of identity or how people feel about themselves (Hubbard, Kidd, and Kearney 2010; Blaxter 2004; Kelly and Millward 2004). Illness experiences reflect health loss and experience data show that survivors feel others perceive them differently after diagnosis (Kelly and Millward 2004; Foster and Fenlon 2011).

There is some debate about whether cancer really is like other chronic conditions (Tritter and Calnan 2002). Cancer is described as differing in three key ways. The first is that it is mainly treated in the secondary care setting of the hospital compared to most other chronic conditions which are treated in primary care. The treatment environment impacts on the experience of care. Chronic condition treatment in primary care is often planned

and proactive while the secondary care treatment of cancer is more often reactive with referral back to primary care at treatment completion (Kadu and Stolee 2015; Mays 2013). Second, the impacts of cancer and cancer treatment are often substantially greater and life-threatening. Tritter & Calnan (2002) argue that classifying cancer as a chronic condition minimises these toxic and substantial impacts and does a disservice to survivors. Third, different cancers and cancer treatments are associated with different side-effects and risks of late-effects. The impacts on individuals can differ greatly based on cancer type and treatment type. This variability and unpredictability in impacts prompted these authors to question whether engagement in self-management is realistic for survivors. This question remains unanswered but there is an extensive literature on the potential benefits for survivors presented in Chapter three.

The common intermittent yet lingering impacts of cancer on physical and psychosocial health indicate that cancer may fit classification as a chronic condition (National Health Committee 2007a). Cancer is currently treated as an acute condition within NZ health services but it is increasingly conceptualised as a chronic condition in global health policy (World Health Organization 2014). This conceptual shift is likely to have implications for care delivery. A paradigm shift from cancer being treated as an acute and self-limiting condition to one that is long-term and chronic, requires redesigned care pathways addressing survivorship care (Lee et al. 2012). Therefore, care pathway redesign in light of chronic care approaches is indicated for further research.

Chronic illness-based approaches in cancer survivorship

Chronic illness-based approaches in cancer survivorship focus on increasing wellbeing through preventing reoccurrence of acute symptoms and minimising adverse consequences (Hewitt, Greenfield, and Stoval 2006). According to the literature, there are three key problem areas for people managing chronic conditions. These are: 1) medical management including taking medications and changing diet, 2) creating and maintaining new and meaningful life roles regarding jobs, family and friends; and, 3) coping with the anger, fear, frustration and sadness of having a chronic condition (Corbin and Strauss 1988).

There are established chronic condition self-management programs delivered internationally that address these key problem areas (Bodenheimer et al. 2002; Lorig et al. 2001; Lawn et al. 2015; Australian Capital Territory Department of Health 2013; Johnston

et al. 2012). Chronic condition self-management has various definitions. The nationally agreed definition in Australia states that chronic condition self-management is “a process...directed toward managing the impact of the disease or condition on all aspects of living by the patient with a chronic condition. It includes, but is not limited to, self-care and it may also encompass prevention” (NHPAC 2006). The following principles are believed to contribute to this process:

- Having knowledge of the condition and/or its management
- Adopting a self-management care plan agreed and negotiated in partnership with health professionals, significant others and/or carers and other supporters
- Actively sharing in decision-making with health professionals, significant others and/or carers and other supporters
- Monitoring and managing signs and symptoms of the condition
- Managing the impact of the condition on physical, emotional, occupational and social functioning
- Adopting lifestyles that address risk factors and promote health by focusing on prevention and early intervention
- Having access to, and confidence in the ability to use support services (National Health Priority Action Council 2006; Australian Capital Territory Department of Health 2008; Australian Capital Territory Department of Health 2013).

Chronic condition self-management has not been extensively explored in the setting of cancer survivorship. Part of the reason for this evidence gap relates to ongoing debate on whether cancer legitimately classifies as a chronic condition (Tritter and Calnan 2002).

In 2009, Naus et al. published a cancer survivorship care model based on the conceptualisation of cancer as a chronic illness. The Cancer Survivor Adaptation Model was comprised of three components: personal context, adaptation process, and quality of life outcomes (Naus et al. 2009). Personal context referred to a persons' beliefs and lifeworld in which the cancer was experienced. Adaptation process was identified as an ongoing and dynamic goal appraisal process. Quality of life outcomes were identified as the main outcomes impacted in both positive and negative ways. The Cancer Survivor Adaptation Model highlighted the importance of evolving survivor goals, non-static

adaptation processes and domain-specific quality of life measures including distress, goal satisfaction and perceptions of control. The model indicated a place for long-duration interventions to support survivors with goal adaptation and identity change. The Cancer Survivor Adaptation Model proposed that survivorship interventions needed to provide long-term support for survivors' evolving priorities and goals in order to increase perceptions of control and quality of life (Naus et al. 2009).

Building on Naus' (2009) work, two Johns Hopkins University nurse scholars applied Corbin & Strauss' 1985 Illness Trajectory Framework to cancer survivorship (Klimmek and Wenzel, 2012). The original Corbin & Strauss Illness Trajectory Framework was developed from in-depth interview data with 60 couples managing chronic diseases (Corbin and Strauss 1985; Corbin and Strauss 1988; Klimmek and Wenzel 2012). The researchers relied on grounded theory to more generally raise awareness of the invisible work associated with chronic illness management at home. The Adapted Illness Trajectory Framework identified the ways in which illness-related work, biographical work, and everyday life work interact for survivors. Klimmek and Wenzel provided examples of tasks and how they link with survivorship work which are reproduced in Tables 1-3 (Klimmek and Wenzel 2012).

Table 1: Domains and tasks of illness-related work

Illness-related work domain (examples)	Tasks and examples
Regimen work	Adhering to prescribed therapies and recommendations <ul style="list-style-type: none"> • Obtaining necessary medications and supplies • Learning the medication regimen and exercises • Reconstructive surgery • Lifestyle modifications • Scheduling and coordinating treatment visits
Symptom management	Managing symptoms or late effects <ul style="list-style-type: none"> • Monitoring and reporting symptoms to health and supportive care workers • Managing ongoing symptoms • Preventing or managing late effects of cancer treatment • Managing psychological sequelae (e.g., delayed distress, post-traumatic stress disorder)
Care planning and maintaining continuum of care	Maintaining the continuum of cancer care <ul style="list-style-type: none"> • Transitioning back to community and primary care • Communicating needs, treatment, and survivorship care plan to all health and supportive care workers

Source: Klimmek and Wenzel 2012, E502

Table 2: Domains and tasks of biographical work

Biographical work domain (examples)	Tasks and examples
Contextualising	Putting the cancer experience into context, including <ul style="list-style-type: none"> • Seeing cancer and its consequences as part of everyday life • Integrating survivorship care and follow-up into daily life
Coming to terms	Coming to accept the implications of cancer and cancer survivorship by <ul style="list-style-type: none"> • Experiencing limitations or changes • Reviewing implications of these changes • Searching for meaning and reconciling • Relinquishing one's former expectations and grieving losses • Restructuring perspective • Looking toward the future
Reconstituting identity	Adjusting to changes in one's identity, including: <ul style="list-style-type: none"> • Physical • Sexual • Social • Spiritual • Psychological Integrating one's identity into a new conceptualization of wholeness around limitations or consequences of cancer
Recasting biography	Giving new direction to one's life plans, including <ul style="list-style-type: none"> • Managing uncertainty and growing as a survivor

Table 3: Domains and tasks of everyday life work

Everyday life work domain (examples)	Tasks and examples
Relationship work	Maintaining, renewing, or resolving social relationships, including <ul style="list-style-type: none">• Negotiating intimacy and sexual relationships• Managing others' unhelpful attitudes and expectations• Educating friends, family, and colleagues• Protecting loved ones from impacts of cancer
Occupational work	Performance of paid or unpaid formal work duties, including <ul style="list-style-type: none">• Adjusting job duties as a result of limitations or symptoms• Negotiating return to work, employment transitions, or job loss• Dealing with issues of workplace discrimination
Emotional and psychological work	Managing variable emotions in response to feeling rules, including <ul style="list-style-type: none">• Putting on a "game face" or brave front• Coping Maintaining or improving one's psychological wellbeing, including <ul style="list-style-type: none">• Managing daily and long-term stress• Managing prior mental health issues such as depression
Health maintenance	<ul style="list-style-type: none">• Management of prior health issues or chronic conditions
Housekeeping	Maintaining the household, including <ul style="list-style-type: none">• Modifying home environment to accommodate any loss of function• Housekeeping, shopping, cooking, yard work, and home maintenance

Source: Klimmek and Wenzel 2012, e505

The Adapted Illness Trajectory Framework provides a useful foundation to describe the work of cancer survivorship (Klimmek and Wenzel 2012). It succinctly highlights the diversity of issues faced by survivors and potential strategies that could be addressed by tailored intervention. The framework also supports survivorship intervention initiating during treatment to support illness-related work. The Adapted Illness Trajectory Framework informed the qualitative phase one study discussion guide and the delivery of the intervention in phase two. This is discussed in more detail in the results and discussion chapters.

Māori whānau-centred care

Māori are tangata whenua, the indigenous people of NZ. The life-worlds of the groups referred to as tangata whenua and tangata tiriti (i.e. non-Māori New Zealanders) differ with respect to history, culture and social influences (Metge 1995). Perspectives on health and wellbeing differ between the two groups (Jansen, Bacal, and Crengle 2008; Walker et al. 2008).

The published models of Māori health integrate key elements that reflect priority values for many Māori. Mason Durie's foundational Te Whare Tapa Whā model integrates four key elements as cornerstones of the whare or house that reflect Māori views on health and wellbeing (Durie 1994). The cornerstones represent the physical, the psychological, the family and the spirit which are held in balance when a person is experiencing wellbeing. Tinana represents the physical element. Hinengaro refers to the mental state. Wairua refers to the spirit. Whānau encompasses the immediate and wider family (Durie 1994). Later models contextualised these same four elements within a wider array of influencing environmental elements including te whenua or the land, and te reo the language (Ministry of Health 2015; Pere 2005a; Pere 2005b). Durie's model was adopted in this study because it is a concise foundational model and it is widely used in the health sector (Doherty and Borrell 2013; Central Cancer Network 2016).

Studies of Māori-specific experiences of healthcare have highlighted the application of Māori values and philosophies of health. Reports of Māori-specific experiences of health frequently mention whānau and increasing access to culturally appropriate carers (Cram, Smith, and Johnstone 2003; Kidd et al. 2013). These key considerations have been applied in delivery of programs under the Whānau Ora initiative (Ministry of Health 2008) and in mental health services under the Meihana model (Pitama, Robertson, and Cram 2007). Therefore, these approaches are referred to in this thesis as Maori whānau-centred care.

Cram et al. (2003) published a qualitative Kaupapa Māori study of Māori health experiences and health practices. The authors conducted a content analysis on the transcript data from 28 semi-structured interviews with Māori living in Auckland, NZ. Key themes were identified around holistic health and the important influence of personal, whānau, and societal influences on health and wellbeing. The findings emphasised the importance attributed to wairua (spirituality) and how it contributes to rationalising the

causes of ill health. Other key influences included whānau involvement, whakawhānaungatanga (establishing relationships) with health and supportive care workers, and use of traditional ways (Cram, Smith, and Johnstone 2003). This study contributed evidence on how to deliver respectful and collaborative healthcare that can have a positive impact on the health of Māori individuals, their whānau, hapu and iwi.

Cultural safety is an important aspect of Māori whānau-centred care (Harding 2013; Wepa 2004). Cultural safety is a term developed by nursing educators which emphasised consideration of the impact of one's own culture on practice (Wepa 2004). A recent Kaupapa Māori study by Kidd et al. (2013) explored the views of Māori men with regard to cultural safety in relation to their chronic illness experiences. The authors point to the need for "health services to value the importance of being Māori, and to respond to issues relating to whakamā such as dignity, shyness, and not wanting to draw attention to oneself" (Kidd et al. 2013, 138). Relationship building and respectful engagement have been identified as important themes for the delivery of culturally safe and effective healthcare (Harding, 2013; Kidd et al. 2013; Slater et al. 2013; Wepa 2004).

The Health Equity Assessment Tool (HEAT) was developed to aid intervention assessment and delivery in light of equity considerations (Signal et al. 2007). The HEAT user's guide identified that interventions may be targeted to different levels (i.e. structural, intermediary pathways, health and disability services, and impact) and each requires unique considerations for equity. Published interventional approaches aiming to deliver Māori whānau-centred care emphasised people being treated as resourceful, skilful and strategic problem solvers (Kidd et al. 2013; Maoriora ki te Ao 2010; Padesky and Mooney 2012; Te Puna whanau ora network alliance 2012).

Strengths-based interventions in support of Māori health and wellbeing relate to tino rangatiritanga (Sanders and Munford 2010; Turia 2011; Cram, Smith, and Johnstone 2003). Tino rangatiritanga is often translated to mean self-determination (Moorfield 2005). Self-determination in healthcare requires an approach that supports development of competence, autonomy and relatedness within an individual's physical, emotional, social and cultural environment.

The individual, whānau, and community are holistically and inextricably intertwined in Māori whānau-centred care models. However, these elements are also linked with health determinants in the literature (Slater et al., 2013; Tobias & Turley, 2012). Health determinants refer to the personal, social, economic, cultural and environmental factors

and drivers that influence health status (Blas and Kurup 2010). Within the healthcare environment, care delivery and clinical factors and drivers can be described at different levels of influence on the individual, whānau, and community (i.e. intrapersonal, interpersonal, institution or organisation, community and system levels) (Zapka et al. 2012; Golden and Earp 2012; Lang and Rayner 2012). Interventions are impacted by health determinants related to environmental factors and drivers. Environmental context is an important consideration in health intervention development and delivery that addresses inequity.

Māori whanau-centred care aims to recognise and deliver care that values and addresses the complex and dynamic interactions of person, culture, environment and spirit (Turia 2011). Māori whanau-centred care, based in Māori health philosophies, is a model of care that has been operationalised through Whānau Ora initiatives (Maoriora ki te Ao 2010). In these approaches, holistic consideration is given to the cause and treatment that best marries symptom contexts with a combination of physical, environmental, spiritual and social solutions (Kidd et al. 2013; Slater et al. 2013; Turia 2011). Māori whanau-centred approaches to healthcare integrate collaborative and empowering healthcare to support overall wellbeing delivered using principles of cultural safety. These are also important considerations for intervention research that can address inequities and deliver care that is acceptable for Māori.

Māori health and cancer experiences

The literature points to inequity in cancer care and outcomes for NZ Māori (Hill et al. 2010; Ministry of Health 2015a; Robson et al. 2005; Robson et al. 2010; Shaw et al. 2006). Several studies attribute the inequity associated with cancer care and outcomes to a combination of factors (Hill et al. 2010; Robson et al. 2005; Robson et al. 2010). Proposed factors contributing to inequity include NZ's monocultural-based health system (Dew, Signal et al. 2015; Walker et al. 2008; Hill et al. 2010), lack of recognised cultural competence among health and supportive care workers delivering cancer care (Dew, Signal et al. 2015), and discrimination due to racism (Walker et al. 2008). Each of these factors lead to differential care for Māori cancer patients (Hill et al. 2010).

Cancer diagnosis and treatment pathways in NZ have been identified as challenging for Māori (Cormack et al. 2005; Dew, Signal et al. 2015; Walker et al. 2008). The literature on Māori-specific cancer experiences has established that cancer care delivery fails to meet

Māori needs and expectations (Cormack et al. 2005; Doolan-Noble et al. 2006; Hutt Valley DHB et al. 2006; Slater et al. 2013; Walker et al. 2008). Several studies have shown differences between how the cancer journey is perceived by Māori compared to non-Māori (Dew, Signal et al. 2015; Slater et al. 2013; Walker et al. 2008).

Dew, Signal et al. (2015) conducted a qualitative study in which 34 respondents were interviewed about their access to and experiences of cancer care. The 19 Māori and 15 non-Māori participants were asked to describe their experiences of cancer care. The qualitative interview data were analysed and differences in categorisations and descriptors used were found. Four key areas differentiated between how Māori and non-Māori described their experiences of cancer care. These areas were described as: 1) use of alternative therapies, 2) the bearing of whānau, 3) discrimination, and 4) respect, embarrassment and care. These areas were identified as key contributors to cultural dissonance that impacted on the experience of cancer care for Māori in the NZ health system (Dew, Signal et al. 2015).

Slater et al. (2013) based their study on interviews with 12 Māori cancer patients. The data gathered from these experience accounts highlights the importance of whānaungatanga (relationships). The authors interpret this data to illustrate the importance of building effective established relationships with primary healthcare practitioners as well as Māori health and supportive care workers. These relationships are described as critical foundations for positive experiences and support for patients and whānau affected by cancer (Slater et al. 2013).

A 2008 qualitative study by Walker et al. reported on Māori experiences of cancer and ways to address perceived gaps in care. Results were reported in relation to environmental context incorporating health system, healthcare process and patient-level factors. Key issues of importance for Māori were identified as whānau involvement in the cancer journey, holistic approaches, and recognition of the cultural context as it relates to emotional and spiritual support. The authors identified components of cultural context included recognition of wairua (spirituality), importance of whakawhānaungatanga (relationships), and the role of whakapapa (genealogy). Participant suggestions for improvements to cancer services included better resourcing of Māori providers, cultural competence training for all health and supportive care workers, the use of systems 'navigators', and the inclusion of whānau in the cancer control continuum (Walker et al. 2008).

These three studies conclude that cultural factors and expectations influence healthcare experiences generally, and cancer care specifically. The studies share similarities in findings. For example, each study emphasises the importance of whānau and whānaungatanga for Māori. Although the studies have small sample sizes and the findings are not generalizable to the target population studied, the results show more similarities than differences. Taken together, these results suggest that care delivery expectations are influenced by cultural context. Further, improvements to care delivery for Māori can be informed by consideration of cultural elements with resulting emphasis on relationships, whānau and cultural safety.

The Chronic Care Model

A basic tenet of this thesis is that The Chronic Care Model can inform redesigned survivorship care pathways. A cancer survivorship lens expands the scope of cancer care and “challenges old paradigms that oncology’s work is done after treatment” (McCorkle et al. 2011, 50). If cancer is conceptualised as a chronic condition, then evidence and models relating to optimal care of chronic conditions are relevant. Redesigned care pathways that integrate relevant chronic condition-based approaches in cancer care may be a way forward that is acceptable and equitable.

The Chronic Care Model is described as a framework that identifies principles to support best-practice person-centred chronic illness care in light of structural drivers and organisational configurations (Wagner 1998; Wagner et al. 1996). The Chronic Care Model was developed after a review and categorisation of intervention research for various chronically ill populations (Wagner et al. 1996). Intervention research literature indicates the importance of six elements (Bodenheimer, Wagner, and Grumbach 2002). The key integrating concept for The Chronic Care Model is that successful approaches to chronic care must integrate each of the intervention elements to yield improved outcomes.

The Chronic Care Model demonstrates how productive interactions between an informed activated patient and a prepared proactive practice team are supported by six key elements. The six elements must work in tandem. The Model aims to improve integration and delivery of care for people affected by chronic conditions (Wagner et al. 1996). The Chronic Care Model, illustrated in Figure 5, shows how these six elements align.

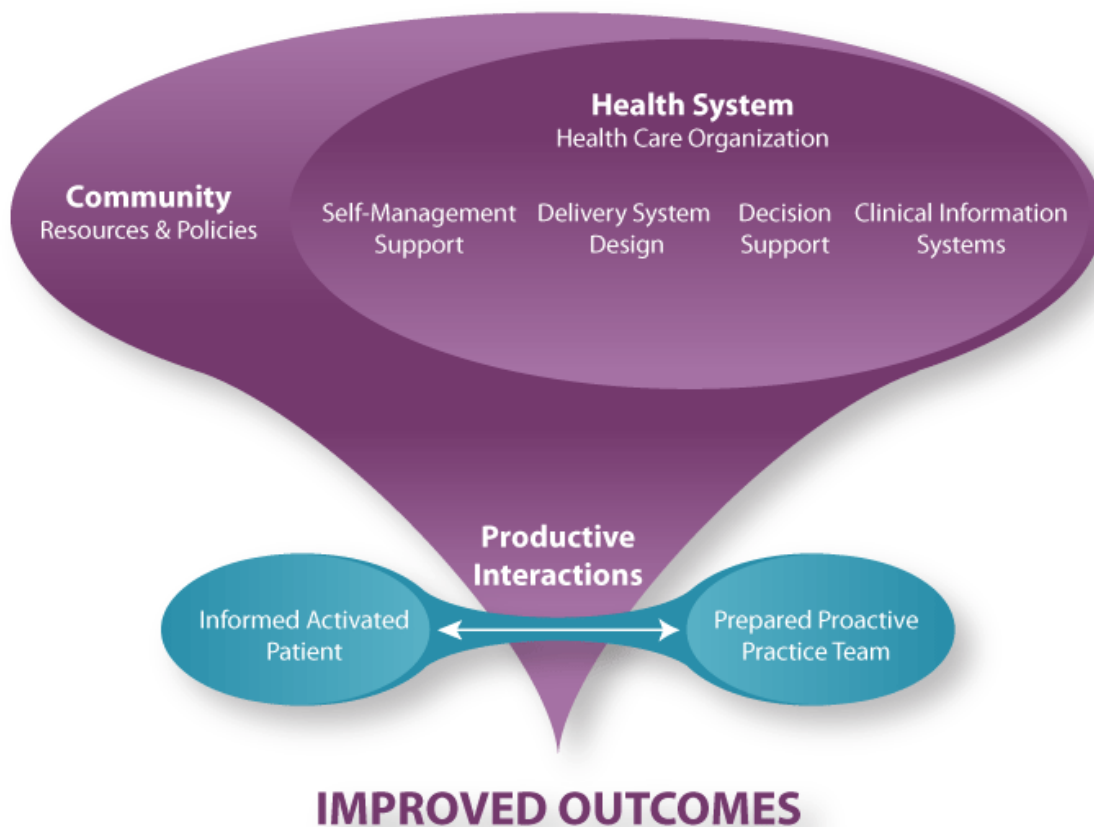


Figure 5: Wagner's (1996) Chronic Care Model

Source: MacColl Institute, 2016

Wagner's model sets out components of best-practice delivery and delivery settings to reach improved health outcomes for people with chronic conditions (Wagner et al. 1996). The Chronic Care Model is based on the concept that productive and planned interactions between health practitioners and patients, fostered by the community and health system, are the basis for improved outcomes. Each of the six elements are derived from a considerable literature base (Bodenheimer, Wagner, and Grumbach 2002; Coleman et al. 2009; Wagner 1998). These elements will each be described in turn.

The first element of the Chronic Care Model is community. This element consists of community programs, local agencies, schools, faith organisations, businesses and clubs that provide support, resources and policies toward improved health.

The overarching health system element is comprised of four sub-elements: self-management support, delivery system design, decision support and clinical information systems. These health care organisation delivered elements aim to support productive interactions and improved outcomes for patients (Coleman et al. 2009). These elements

are equally important and must be considered together. For example, clinical information systems and decision support tools inform options that are accessed by patients through accessible delivery system design. Supported self-management is important to establish a collaborative partnership between healthcare practitioners and people affected by illness to support decision-making on options.

Self-management support as a key element of The Chronic Care Model is described first given that it is the topic of this thesis. “Chronic condition self-management is a process that includes a broad set of attitudes, behaviours and skills” (NHPAC 2006). A comprehensive definition was provided earlier in the chapter on page 36. This process is included as a key element of The Chronic Care Model because the approach has an extensive evidence base (Glasgow et al. 2002; Wagner 1998; Wagner et al. 1996). Since first publication of The Chronic Care Model, self-management support has received growing attention as a way of empowering patients to be partners in the effective management of their health (Bodenheimer et al. 2002; Boger et al. 2015; Chodosh and Morton, 2005; Newbould, Taylor, and Bury 2006; Sarfati et al. 2016). Self-management support has traditionally been delivered via information, online programs, workshops and intervention programs (Foster and Fenlon 2011). A supported self-management program helps people to identify their needs and priorities, in collaboration with health and supportive care workers, resulting in enabling and empowering solutions-based interactions (de Silva and Health Foundation 2011). Established, well-known, evidence-based self-management programs have originated in the USA, UK and Australia (FHBHRU 2005; Lorig et al. 2001; Newbould et al. 2006). The literature review in the next chapter explores self-management and supported self-management programs in more depth.

A second key element of The Chronic Care Model is delivery system design. This element relates to how care is delivered. Evidence shows that care providers that are encouraged to deliver quality care, supported by professional development and clinical leadership, leads to improved patient outcomes (Wagner et al. 1996). The delivery system design element is shown to be best supported by care pathways and evidence-based clinical practice guidelines (Wagner et al. 1996; Wagner 1998).

Decision support is a third key element of The Chronic Care Model. Tools embedded within clinical information systems can inform best-practice treatment options derived from

clinical variables. The element of decision support is about encouraging availability of information tools for delivery of best-practice care by health and supportive care workers.

Clinical Information systems, a fourth key element, incorporates clinical notes as well as results and reminder systems in electronic health records. Registries, to catalogue disease incidence, mortality and, at times, care management are included under this element.

For people affected by chronic conditions, an active role in care management has been identified as an important aspect of productive interactions and improved outcomes within The Chronic Care Model (Coleman et al. 2009; Bodenheimer, Wagner, and Grumbach 2002). There is growing emphasis globally being placed on encouraging active and expert patients that want to collaborate in their healthcare and wellbeing (Wilson 2008). In NZ, person-centred care based in collaboration is indicated by key NZ policy documents. Two of the guiding principles of the NZ Cancer Control Strategy are that activities should “reflect a person-centred approach” and “actively involve consumers and communities” (Minister of Health 2003b). However, research does indicate that not all people want the same type of participation in person-centred care. Individual characteristics that have been found to present a barrier to person-centred care have included 1) unwillingness to appear ignorant; 2) uneasiness in communicating within a perceived power imbalance i.e. with a member of a higher social class; 3) provider reluctance to share control of the interaction, and/or; 4) patient concession to expert authority (Roter 1977). By applying chronic care approaches that are proactive, planned and population-based, work towards achieving personalised person-centred cancer care in NZ may become less aspirational and more operational.

The Chronic Care Model has been applied and reviewed in numerous studies aiming to improve chronic illness management in various health care settings (Barr et al. 2003; Battersby et al. 2010; Coleman et al. 2009; Kadu and Stolee 2015; Pearson et al. 2005). The 2008 ABCC study aimed to provide standardised guidance to improve NZ DHB effectiveness and efficiency of health service delivery using The Chronic Care Model as a foundation (Connolly 2011). The ABCC study followed-on from the 2007 National Health Committee recommendation that DHBs set disease-management programs within the Chronic Care Model in order to ensure effectiveness, and that generic disease-management programs be developed in preference to single disease-management programs (Connolly 2011; National Health Committee 2007a). Some DHBs were found to

be effectively delivering healthcare within The Chronic Care Model, but standardised implementation was needed and further evidence-based research was recommended.

Part two summary

The literature shows that cancer impacts on life and challenges self-management. Cancer survivors report visible and invisible impacts related to living with, through and beyond cancer. These impacts create vulnerabilities that are experienced and described differentially across individuals and groups. Cancer-related impacts are common, personal, variable across time and wide-ranging.

Models of care provide useful guides to deliver intervention that may address survivorship impacts. Various models can be used to guide intervention research. The foundational Māori health model, Te Whare Tapa Wha, fits the holistic nature of cancer survivorship impact described in the literature and is well-regarded in the NZ health context (Durie 1994).

A key consideration for survivorship intervention in NZ is equity and acceptability for Māori. Delivery of intervention that is acceptable for Māori, can be informed by Māori whānau-centred care approaches. These aim to prioritise establishing relationships and inclusion of whānau, alongside using cultural safety and strengths-based approaches, in supportive environmental contexts.

The diversity of work of cancer survivorship has been described using the Adapted Illness Trajectory Framework (Klimmek and Wenzel 2012). Cancer survivors manage variable and intermittent holistic impacts both during and post-treatment. Therefore, intervention at the front-end of the cancer trajectory is considered to have potential utility to support survivorship work during and post-treatment.

The Chronic Care Model integrates various elements relevant for any healthcare intervention (Wagner et al. 1996). It is a well-regarded and evidence-based model of care that can inform intervention relevant to the NZ survivorship context. The impacts of cancer are often chronic but there is debate as to whether classifying cancer as a chronic condition is useful. The cancer trajectory is different from other chronic conditions pathways so it is unclear if chronic care interventions can be transplanted to support cancer survivorship. However, chronic conditions research has a long history and provides a strong foundation for exploring cancer survivorship approaches. Further, The Chronic

Care Model is not prescriptive and can include priorities derived from Māori whānau-centred care approaches.

In summary, this part two section of the background chapter highlights survivorship impacts and models of care. Based on the evidence, three models were presented and described as relevant to address the research questions: Te Whare Tapa Wha (Durie 1994), the Adapted Illness Trajectory Framework (Klimmek and Wenzel 2012), and The Chronic Care Model (Wagner et al. 1996). The Te Whare Tapa Wha model illustrates the wide-ranging impacts that characterise Māori health philosophies and perspectives (Durie 1994). The Adapted Illness Trajectory Framework describes the work of cancer survivorship (Klimmek and Wenzel 2012). The Chronic Care Model shows six key principles that work in tandem to deliver best-practice chronic conditions care (Wagner et al. 1996). These three models were drawn upon to guide the two-phased intervention program research presented in this thesis.

Part three: Intervention

Quality improvement is a primary aim of the NZ health system (Minister of Health 2003a; Minister of Health 2016a). Research into health interventions can provide evidence for approaches that progress quality health delivery toward better care, efficiencies and service improvement (The Health Foundation 2013). Health interventions were defined in a 2000 UK National Institute for Clinical Excellence report as “drugs, devices, procedures and the organisational and support systems within which healthcare is delivered” (National Health Committee 2005).

Healthcare interventions include roles, policies or programs put in place as “a set of actions with a coherent objective to bring about change or produce identifiable outcomes” (Rychetnik et al. 2002). Interventions can target improvements in patient-reported outcomes, clinical care outcomes, or organisational and system outcomes (The Health Foundation 2013; World Health Organization 2006).

Service delivery interventions are of a wide variety and can be categorised in many ways. For example, one way to categorise a service delivery intervention is to identify the level on which the intervention is targeted. Effective interventions are influenced by, and may impact on, outcomes at the individual or intrapersonal level, interpersonal or family and care team level, institutional or organisational level, and systems levels (Golden and Earp 2012). These levels provide a means to categorise interventions as well as to identify enablers and barriers to intervention delivery. Examples of interventions aimed at the structural level are national or organisational policies. Institutional level interventions target improvements in resources or policy at the organizational level. Interpersonal-level interventions aim to create change in social relationships between members of a family or with a care team. Intrapersonal level interventions target change in the knowledge, belief or skills of individuals. Ideally interventions target more than one level, but interventions targeting more than one level have been identified as difficult to administer due to structural barriers such as limited resources (Golden and Earp 2012).

Multiple factors and drivers impact on intervention acceptability, feasibility and effectiveness. Examples of factors or drivers that impact on interventions are change champions and resource availability (The Health Foundation 2014). The level of impact of any intervention is affected by personal and environmental factors. Important considerations for monitoring intervention acceptability, feasibility and effectiveness are

fidelity and scaling. An intervention study with high levels of fidelity is reproducible (Carroll et al. 2007; Horner, Rew, and Torres 2006). Scaling a study involves a series of processes to introduce interventions, within an existing context, through a program delivery structure that accounts for enablers and barriers, with the aim of improving coverage and equitable access to the intervention (Mangham and Hanson 2010).

Analytical frameworks, such as RE-AIM, have been developed to guide intervention implementation and evaluation within the environmental context (Glasgow et al. 2001; Glasgow 2002; Glasgow et al. 2006; National Cancer Institute Cancer Control Science Implementation Team 2012). RE-AIM is a well-known and widely utilised scientific framework and checklist for assessing the strengths and weaknesses of interventions in real-world settings, with emphasis on implementation fidelity (Glasgow et al. 2001; National Cancer Institute Cancer Control Science Implementation Team 2012). RE-AIM stands for reach, effectiveness, adoption, implementation and maintenance (Glasgow 2002). This analytical framework supports evaluation of complex health service interventions across relevant domains to inform intervention adaptations required in feasibility studies that lead to improved randomised or multi-site trials.

Evaluation theory postulates that interventions themselves do not result in improved outcomes (Astbury and Leeuw 2010). They, instead, generate mechanisms that may impact on behaviours of individuals and organisations that can affect outcomes (Keating 2014; Astbury and Leeuw 2010). Identifying causal mechanisms that deal with complex systems and service users can be difficult. Although proving causality and effectiveness in intervention studies is fraught and difficult, “identifying mechanisms that link cause and effect relations is crucial for the development of deeper and more fine-grained explanations of social phenomena” (Astbury and Leeuw 2010, 363). In the context of this thesis, it is unlikely that the complexity of survivorship can be addressed by a single intervention. However, it is hoped that insights can be developed incrementally over multiple studies generating increasing evidence.

Complex intervention framework

Humans and the systems they create are complex systems because different individuals and organisations can act independently and unpredictably. Therefore, in accordance with Complexity Theory, outcomes from interventions can be surprising and chaotic (Thompson

et al. 2016). An intervention framework assists with outlining an approach that generates multiple types of evidence to evaluate intervention context and possible mechanisms to help generate useful outcomes and insights into causality.

The UK's Medical Research Council (MRC) has published guidance on complex interventions (MRC 2009) in an attempt to develop a standardised approach that recognises that interacting intervention components may result in variability of outcomes. The MRC document *A Framework for the Development and Evaluation of Randomised Controlled Trials for Complex Interventions* states that "the greater the difficulty in defining precisely what exactly are the 'active ingredients' of an intervention and how they relate to each other, the greater the likelihood that you are dealing with a complex intervention" (MRC 2000, 1).

The framework document published by the MRC in 2000 outlined a linear phased approach to randomised controlled trial (RCT) design (MRC 2000). The sequential framework consists of five steps. The 'pre-clinical' or **theoretical phase** is step one whereby interventions and their proposed mechanisms of action are identified from the literature. Identified confounders and strategic design issues associated with interventions are also reviewed in this first step. Step two is referred to as the **modelling phase**. It involves developing a deeper understanding of intervention components and how they may inter-relate through computer simulations or qualitative testing. Step three is the **exploratory trial phase** whereby a protocol is tested out in a real world setting. Step four is the **definitive RCT phase** using a tested protocol that is defensible, reproducible and adequately controlled. Step five is the **long-term implementation phase** which entails a separate study to establish the real-life effectiveness of the intervention over time. The framework emphasises good practice methodology for informing development of RCTs outlining a focus on identification of the mechanisms or key ingredients of a complex intervention that produce effects or outcomes (MRC 2000).

In 2008, the MRC published updated guidance that evolved their vision from a linear approach to one that enabled increased flexibility and allowed for refinement across and between phases (Craig et al. 2008). In hindsight, the MRC noted that health interventions require coordinated efforts at multiple points which was not reflected by the original approach (Sahasranaman 2011). The key difference between the updated model and the original one is the iterative and flexible approach as well as a recognition that multiple approaches to multi-site study-designs beyond the RCT were valid and useful. The

updated, iterative framework, shown in Figure 6, informed the methods for the studies reported on in this thesis (MRC 2009).

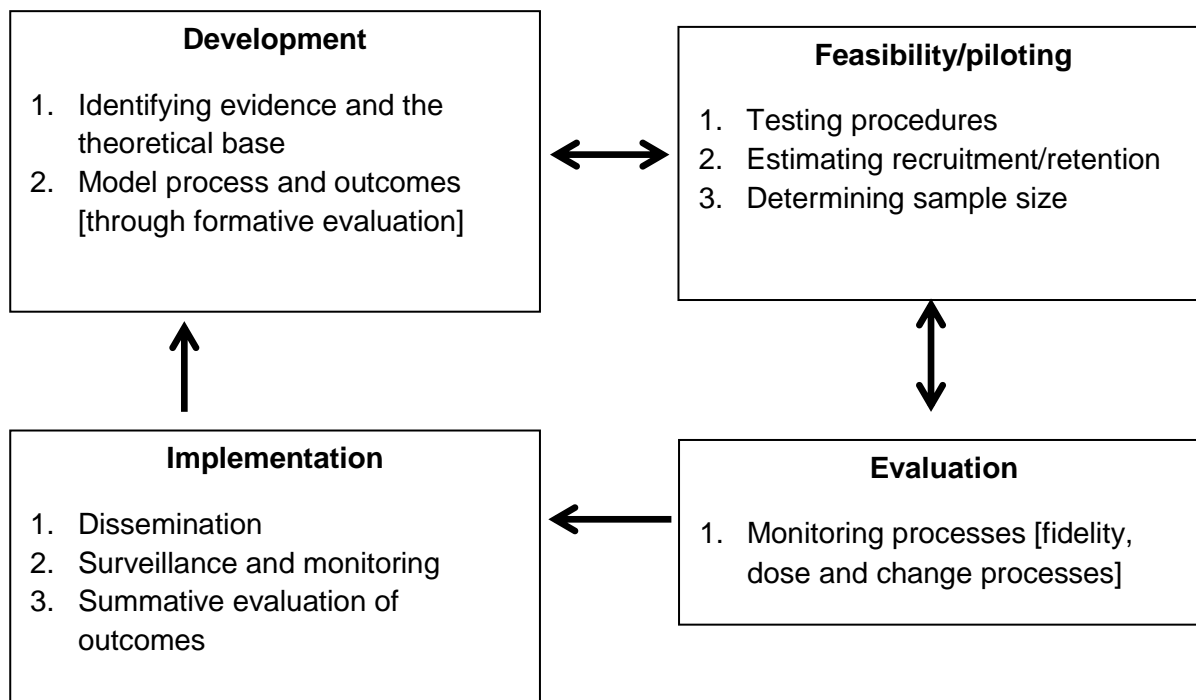


Figure 6: 2009 MRC framework for developing and evaluating complex interventions

The use of the MRC Guidance enables iterations of development and feasibility testing to generate evidence for intervention. The MRC framework was utilised to guide the research presented in this thesis. A phase one qualitative study was devised to ‘model’ the intervention. A phase two randomised single-site exploratory pilot study was envisioned. Ultimately, the goal was delivery of an effective intervention which could be scaled up as one of several standardised cancer survivorship pathways.

Intervention and survivorship

NZ’s cancer care pathways are designed to deliver individual outcomes and to meet system priorities such as addressing disparities, decreasing waiting times, improving access, and sustaining services within a climate of constrained resources (Mays 2013). One recent survivorship intervention delivered in NZ involved introduction of cancer care coordinator roles into hospital-based cancer care settings (Cancer Institute NSW 2011; Collinson et al. 2013). Cancer care coordinators in NZ are generally hospital-based clinical nurse specialists that work with people affected by cancer to help them connect with essential health services and reduce delays in treatment (Collinson et al. 2013). Care

coordination roles enable delivery of support by multiple tools and strategies based on patients expressed needs and priorities. Cancer care coordinators were identified as a cost-effective person-centred intervention in cancer care (Blakely, 2013; Blakely et al., 2015).

In the UK, the National Cancer Survivorship Initiative has provided the overarching structure for delivery of survivorship interventions (National Cancer Survivorship Initiative 2010). Self-management support was included in the 'recovery package' (National Cancer Survivorship Initiative 2013). Redesigned care pathways were tested. Survivors of breast, prostate, colorectal and lung cancers undertook goal assessment and risk stratification to inform novel ways to deliver survivorship care (Oeffinger et al. 2014). An evidence-based report was produced as a basis to guide delivery of interventions aiming to improve survivorship outcomes (National Cancer Survivorship Initiative 2013).

In Australia, a series of demonstration projects have taken place. In 2011, the Victorian state government in Australia funded six two-year cancer survivorship demonstration projects targeting post-treatment transition (Jefford et al. 2015). The projects included shared care and nurse-led delivery models and supported self-management/wellness interventions. The projects' process and project-specific outcomes were compared and reviewed. The enablers and challenges/barriers for the projects were presented in a tiered ecological categorisation at the individual, organisation and system levels. Individual enablers included patient readiness to engage in survivorship tasks while the barriers for health practitioners were identified around terminology and lack of flexibility in project delivery. Organisational enablers included clinical champions and staff recognition of survivorship issues while the barriers were cited as organisational processes that could not readily identify transitioning survivors, lack of individual readiness for change, time-consuming interventions constrained by appointment time expectations, and difficulty measuring cost and outcomes. The need for risk-stratified pathways and development of survivorship priority and unmet needs assessment were emphasised. System enablers included workforce education and training, existing relationships with primary care, and partnerships with community providers. The system barriers included lack of tools and ways to implement needs assessment and risk stratification. The overall conclusion was that early preparation of patients for survivorship with tailored interventions was useful, but delivery was challenging due to individual, organisational and system barriers.

Summary of background chapter

Cancer survivors represent a growing segment of the population. Increases in cancer survival are an epidemiological trend that has informed research directions in the discipline of public health. The impacts of cancer cut across social, physical, emotional and spiritual domains. These impacts sometimes have a significant lingering effect on the wellbeing of individuals and whānau affected by cancer. Interventions may be useful to address these impacts and improve care delivery.

Models of care inform intervention delivery. Durie's 1994 Te Whare Tapa Wha model provides a framework to view health and wellbeing from a Māori perspective. It is used to guide understanding and delivery of culturally safe interventions that aim to reduce inequities. Cancer is increasingly classified as a chronic condition. Wagner's 1996 Chronic Care Model provides a framework that fits with cancer survivorship. Supported self-management is an integral element of this model.

The MRC guidance on complex interventions provides an established framework for development and monitoring of intervention delivery. The broad aim of this research is to deliver an intervention that can trigger improvement in the care and outcomes for cancer survivors. This research is needed because improvements in cancer survival have not been paralleled by development of care pathways that adequately address the ongoing needs of survivors. This research is based on use of an intervention framework, guided by models of care, to support intervention delivery.

CHAPTER 3: Supported self-management and cancer survivorship

This chapter presents the evidence and rationale for implementing and evaluating supported self-management as a potential intervention to support cancer survivors. The background information provided in Chapter two described increasing numbers of cancer survivors as well as persistent inequities in cancer care and outcomes. The issue being addressed in this thesis is that cancer survivorship is associated with long-term, often chronic, impacts and ongoing problems. These impacts span across the Te Whare Tapa Wha four cornerstones of health and wellbeing: physical, emotional, spiritual and social (Durie 1994). The Chronic Care Model was chosen as a guiding framework for intervention identification aimed at exploring this gap in survivorship care (Wagner et al. 1996). Interventions and a guiding intervention delivery framework, The MRC Guidance on Complex Interventions, was then described to inform the methodology to proceed (MRC 2009).

Supported self-management intervention programs are person-centred approaches with potential applicability in NZ cancer care pathways. First, working definitions of self-management and supported self-management are presented in this chapter. A brief history of the development of supported self-management, its theoretical foundations, and three structured programs are then outlined. The enablers and barriers of supported self-management interventions are summarised in order to establish the context for choosing one of the three structured programs for implementation in the NZ cancer care context. The final sections summarise the findings from the large and rapidly expanding body of supported self-management literature to outline gaps warranting further investigation.

Self-management and supported self-management

Health self-management occurs when individuals seeking healthcare take one or more actions to manage and monitor their own health and wellbeing. Actions that indicate self-management of health include “eating well, exercising, taking medicines as prescribed, keeping in good mental health, watching for changes, coping if symptoms worsen and knowing when to seek professional help” (de Silva 2011, vii).

Self-management has an extensive literature base. It is variously described as a philosophy (Flinders Health Behaviour & Health Research Unit 2011), a model of care

(Lee et al. 2012) and an intervention outcome (Fowles et al. 2009). In these various manifestations, self-management is always associated with chronic or long-term conditions. Seven principles commonly associated with chronic condition self-management are shown in Figure 7 (FHBHRU 2005; Lawn and Battersby 2009).

Seven principles of chronic condition self-management

Individuals with chronic conditions:

1. Have knowledge of their condition
2. Follow a treatment plan (care plan) agreed with the health professionals
3. Actively share in decision making with health professionals
4. Monitor and manage signs and symptoms of their condition
5. Manage the impact of conditions on the physical, emotional and social life
6. Adopt lifestyles that promote health
7. Readily access support services (NHPAC 2006; Lawn and Battersby 2009)

Figure 7: Seven principles of chronic condition self-management

Early proponents of self-management proposed that effective self-management was indicated by: 1) collaboration with health and supportive care workers; 2) a documented, systematic approach including routine assessment of both parties' priorities and goals; 3) action planning and goal setting that is regularly monitored for effectiveness; and, 4) effective use of resources to support health (Wagner 1998; Clark et al. 1991; Lorig et al. 2001; Bodenheimer et al. 2002). Dr Kate Lorig, an expert in this field and developer of The Stanford Program, one of the first supported self-management programs, defines self-management support programs as follows:

Self-management programs aim to help patients with medical management, maintaining life roles, and managing negative emotions, such as fear and depression. In addition, programs provide patients with the necessary knowledge, skills, and confidence (self-efficacy) to deal with disease-related problems. Finally, self-management prepares patients to collaborate with their health care professionals and the health care system (Lorig et al. 2001, 257).

Self-management is a term associated with various meanings and widely applied. It has been used to describe information delivery, online programs, workshops and programs and many other techniques and tools (NHPAC 2006).

The terms self-management and self-care are often used interchangeably adding to terminology confusion. In the wider context of self-care, self-management can be

considered a way to achieve self-care (Omisakin and Ncama 2011) or as a stand-alone endeavour. Self-care is defined herein as actions taken on one's own. Self-care may include actions taken to reduce the risk of disease (Clark et al. 1991; Omisakin and Ncama 2011) or to preserve identity, function and normality (Kidd et al. 2008; Pan et al. 2011). In NZ, indigenous Māori self-care may include traditional practices, called rongoa, that supports wellbeing via plant-based medicines and massage (Dew et al. 2015). More broadly, self-care differs from supported self-management because self-care practices and applications may occur away from the purview of health and supportive care workers.

Supported self-management involves “engaging in activities that protect and promote health, monitoring and managing the symptoms and signs of illness, managing the impact of illness on functioning, emotions and interpersonal relationships, and adhering to treatment regimes **in partnership** with health professionals and community resources” (Center for the Advancement of Health and Center for Health Studies of the Group Health Cooperative of Puget Sound 1996, 1). Supported self-management is one of the six key elements of The Chronic Care Model (Glasgow, Orleans, and Wagner 2001). The overarching aims of supported self-management interventions are to inspire and foster use of skills and strategies by the person accessing healthcare for collaborative problem-solving, health monitoring and decision-making enabled and empowered by a partnership with health and supportive care workers (Chodosh and Morton 2005).

Information on supported self-management was sourced from the English language literature captured in two major databases, Medline and Google Scholar, as well as from the grey literature identified in NZ and Australia. The terms ‘self-management’ and ‘self-care’ alongside ‘cancer’, ‘neoplasm’ and ‘oncology’ were entered as search terms with results limited to between 1996 and 2015. Studies were restricted to English language reports with the target population being adults. The term ‘intervention’ was later added in to narrow down the results. An abstract review on just over 20,000 abstracts was conducted on the Medline results to help with narrowing the scope of the results of interest from the Google Scholar search field. Due to the size and range of the literature, this literature is presented as a narrative review rather than a formal systematic review. Further, this literature review summarizes meta-analyses prior to highlighting and critiquing individual self-management studies.

This thesis focuses on delivery of a supported self-management program for people living with, through and beyond cancer. Within that context, self-management is noted to occur

when individuals take responsibility and actions to manage and monitor their physical, psychological, social and spiritual wellbeing while living with, through and beyond cancer.

Foundations of supported self-management programs

Supported self-management programs can be delivered as complex interventions that aim to systematically improve the way individuals self-manage chronic conditions and achieve a sense of wellbeing (Mills et al. 2014). These programs are complex interventions because they consist of multiple active ingredients that cover multiple topics delivered with various formats and strategies (Mills et al. 2014; MRC 2000). Supported self-management programs differ from other complex interventions targeting wellbeing because this approach is specifically structured around systematically fostering a partnership with health and supportive care workers (de Silva and Health Foundation 2011). Substantial evidence has been generated over the last 35 years to support improved health outcomes resulting from partnerships enabled and inspired by supported self-management approaches or programs. The historical foundations for this approach are critically reviewed in this section.

In 2016, there is still no gold standard definition for self-management support. This thesis adopts the IOM definition of supported self-management:

the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support (Institute of Medicine 2003, 52).

Over the years, the term self-management has been widely used as an intervention descriptor. This has led to discourse differences and contributed to wide variation in the way the term 'supported self-management' has been applied in the literature. The authors of supported self-management meta-analyses reviewed in this section describe wide variation in interventions delivered under this classification which contributes to methodological confusion. This state-of-affairs appears to limit the understanding of self-management terminology and practice. It also contributes to a lack of comparability between various self-management programs. In order to categorise the numerous supported self-management programs reported in the literature, these programs have been differentiated from self-management promotion and education programs (Gao and

Yuan 2011). Table 4 identifies key variables that differentiate between these two types of self-management programs as described in the literature.

Table 4: Differentiating between two interpretations of self-management

	Supported self-management programs	Self-management promotion and education programs
Program focus	Partnership Collaborative problem-solving	Patient education and disease-specific information delivery
Offerings	Problem identification, decision-support, collaborative identification of actions and alternative options, care planning	Information, discussion points and technical skill practice
Issues defined by	Person receiving healthcare and healthcare practitioner	Health and supportive care workers
Outcome indicators	Self-efficacy, QOL	Knowledge measures and clinical indicators
Disease orientation	Can address comorbidity and complexity	Disease-specific
Key factors	Health provider competencies delivered by way of skills and strategies to support individual and whānau motivation and self-efficacy	Health seekers with low health literacy or health confidence are optimal target group
Examples	The Flinders Program™ The Stanford Program The Expert Patients Program	Living with Cancer Education Program Kia ora – E te iwi

Supported self-management intervention programs differ from self-management promotion programs in program focus, tools, who defines problems, preferred outcome indicators, disease orientation and key contributing factors. There is no specific and accepted global definition of supported self-management and few core program components agreed as critical for successful program delivery (Warsi et al. 2012). In this thesis, attention to partnership and collaborative processes, fostered between a person seeking care, and health and supportive care workers, are regarded as key indicators of a supported self-management intervention program.

In summary, supported self-management intervention programs are a subset of self-management approaches. They are classified as complex interventions and include collaboration as a key component.

Supported self-management programs

Supported self-management programs, delivered by health and supportive care workers, aim to enable, inspire, empower and up-skill individuals affected by chronic health conditions, to take action in home and community settings to manage their physical, psychological, social and spiritual wellbeing (Bycroft and Boyd 2011). Supported self-management programs prioritise collaboration as the basis for encouraging development of tailored strategies to support problem-solving and decision-making (Bodenheimer, McGregor, and Sharifi 2005).

Research and development into supported self-management programs began in the 1970's. Early programs were disease-specific. Diseases for which supported self-management programs were developed included asthma (Beasley, Cushley, and Holgate 1989; D'Souza et al. 1994), diabetes (Counties Manukau DHB 2016; Fisher et al. 2005; Williams et al. 2005), arthritis (Lorig et al. 2001), and heart disease (Clark et al. 1991). Published NZ literature from the 1990's described effectiveness of supported self-management programs for New Zealanders diagnosed with asthma and diabetes (D'Souza et al. 1994; Counties Manukau DHB 2016). Overseas evaluation studies of disease-specific programs identified improvements in various clinical and functional health outcomes but results were found to be inconsistent, especially in studies working with older adult cohorts (Chodosh and Morton 2005).

Clark et al. (1991) published one of the earliest reviews of supported self-management. The authors summarised available literature across five chronic conditions to ascertain if there was any consensus on self-management tasks supported. They identified four sets of self-management tasks that could empower people to reach optimal outcomes in chronic condition management. The first set of tasks involved promotion of motivation to develop and use strategies for wellbeing. The second set of tasks involved collaborative monitoring and management of the condition through partnership between individuals seeking care, and health and supportive care workers. The third set of tasks involved introduction and use of tools to build self-efficacy. The fourth set of tasks aimed to empower individuals to maintain life roles which was deemed important for self-esteem

and relations with others. The study concluded that the key tasks of supported self-management fell into two distinct categories: at-home management and psychosocial coping (Clark et al. 1991).

Contemporary generic supported self-management programs incorporate findings from earlier disease-specific programs. Standardised programs aim to link approaches that can address both the at-home and psychosocial tasks identified by Clark et al. (1991). In the late 1990's, non-disease specific supported self-management programs began to emerge. These generic programs integrated collaborative problem-solving, goal-setting, skills for drawing on community resources, and motivational strategies to support, enable and inspire individual and family collaboration and decision-making with health and supportive care workers.

In 2002, Barlow et al. systematically reviewed the growing international literature on generic, cross-condition supported self-management intervention. The review aimed to assess approaches to self-management and their effectiveness. The largest numbers of studies reviewed were from the USA and most programs described were aimed at people with asthma, diabetes or arthritis. Approaches included group-based, individual or a combination of both. About half of the studies published were shown to be underpowered RCTs with short follow-up timeframes. The authors found that supported self-management interventions showed wide variation in practice and that this variability impacted on the ability to assess and compare outcomes. The authors concluded that self-management programs can provide benefits for participants, particularly in the short-term for self-efficacy. They recommended that future studies incorporate longer term follow-up with more disease-related and psychosocial outcome measures (Barlow et al. 2002).

Two years later, Warsi and colleagues' (2004) published another systematic review of supported self-management studies across multiple chronic conditions (Warsi et al. 2012). They limited their review to chronic disease self-management intervention studies that assessed clinical outcomes and used control groups. They concurred with Barlow et al. (2002) regarding the variability in methodology and reporting associated with supported self-management programs. They concluded that supported self-management programs did improve some clinical outcomes for select chronic diseases. Face-to-face delivery of support was the most important variable associated with improved outcome. The authors noted the need for tailoring interventions due to various strategies and tools being required by different individuals for different conditions at different times (Warsi et al. 2012).

Chodosh et al. (2005) conducted a meta-analysis of self-management for older adults diagnosed with three specific chronic conditions: osteoarthritis, hypertension and diabetes mellitus. They identified clinically and statistically significant improvements in some clinical outcomes for diabetes and hypertension. However, they concluded that there was a lack of agreement on self-management program definition and no mechanisms of action identified which seemed to impact on program uptake (Chodosh and Morton 2005).

Across these three self-management meta-analyses, the evidence suggests that self-management approaches can be effective in helping individuals improve self-efficacy and make improvements in various health-related outcomes (Warsi et al. 2012; Chodosh and Morton 2005; Barlow et al. 2002). Reviewed studies have shown that supported self-management programs have been associated with improvement in quality of life and clinical outcomes. It has been suggested that these interventions also reduce healthcare resource utilisation use but the data on this outcome is equivocal (Health Foundation 2011, 17). These meta-analyses identify general methodological limitations in supported self-management intervention studies related to small sample sizes, no clear identification of key program elements, and lack of long-term follow-up.

Theoretical foundations

The mechanisms of action involved in generating the impacts of supported self-management programs on outcomes remain unclear (Chodosh and Morton 2005). The theories associated with successful self-management are predominantly psychological theories of individual behaviour. These include self-efficacy theory (Bandura 1982; Lev 1997; Bandura 1977), social cognitive theory (Bandura 1986), goal-setting theory (Locke and Latham 2013) and coping theory (Folkman and Lazarus 1982).

Self-efficacy is the most common outcome targeted by supported self-management approaches (Battersby, Lawn, & Pols 2010; Bodenheimer, Lorig, et al. 2002; Gallagher et al. 2008; National Institute for Health and Clinical Excellence 2007; Schrank et al. 2012; Wilson 2008). Self-efficacy relates to an individual's perception of skills and abilities to act effectively and competently to achieve tasks in a given situation (Bandura 1977, 472). Bandura proposed that individuals can increase their self-efficacy and perception of their self-competence through increased awareness and practice (Bandura 1977). Increased self-efficacy for health management has been associated with decreases in negative

psychological states and greater motivation to set realistic health goals and attain them (Lev 1997).

Cognitive behavioural strategies, including problem solving, goal setting and action planning, have been shown to increase self-efficacy (Kahl, Winter, and Schweiger 2012; Padesky and Mooney 2012). A 2006 meta-analysis, comparing cognitive behavioural strategies versus patient education alone, suggest cognitive behavioural strategies were more effective in helping cancer survivors to cope with short-term management of depression and anxiety and achieve long-term improvement in QOL (Osborn, Demoncada, and Feuerstein 2006). Supported self-management interventions often utilise cognitive behavioural approaches in efforts to increase an individual's self-efficacy for living with and beyond cancer (Graves 2003).

Bandura expanded self-efficacy research into social cognitive theory, which focused on individuals capacity to consciously change or take action within particular environmental contexts (Bandura 1986). Social cognitive theory is based on the premise that human functioning and regulation is influenced by both personal and environmental factors. People are portrayed as proactive and self-regulating. Therefore, they have the capability to consciously change and take action to develop new or improved coping skills (Bandura 1986). A 2003 meta-analysis of 38 psychosocial intervention RCTs for cancer patients, incorporating QOL as an outcome measures, found that those based in social cognitive theory approaches were associated with improved QOL and psychosocial outcomes (Graves 2003). Graves (2003) concluded "that using social cognitive theory-based interventions maximizes improvement in overall QOL outcomes for adult cancer patients" (210). These findings suggest that supported self-management interventions with social cognitive theory-based elements can generate positive effects on QOL for cancer survivors, but may not result in changes to functional or clinical outcomes.

Goal setting theory describes how the goal setting process can influence individual behaviour (Locke and Latham 2013; Locke and Latham 2006; Locke and Latham 1990). Locke & Latham's theory suggests that self-identified or collaboratively developed goals contribute to goal commitment. The development of Specific, Measurable, Attainable/agreed, Relevant/realistic, and Time-bound (SMART) goals have been suggested as an extension of goal setting theory (Doran 1981). Attaining goals, particularly difficult goals, is suggested to produce a sense of competence and success (Locke and Latham 1990; Locke and Latham 2006; Locke and Latham 2013). Within supported self-

management interventions, goal-setting is incorporated as a way of helping survivors develop strategies and build self-efficacy.

Coping theory describes how emotion and cognitive appraisal processes are used to minimise or deal with stressors (Folkman and Lazarus 1982). There are numerous coping strategies identified in the literature, and relatively few theories of coping. Lazarus and Folkman (1984) categorised coping strategies into two groups: emotion-focused coping and problem-focused coping. Emotion focused coping strategies included distancing, escape-avoidance, accepting responsibility or blame, exercising self-control, and positive reappraisal. Problem-focused coping included self-controlling, information seeking, and evaluating pros and cons (Lazarus and Folkman 1984). Supported self-management interventions often address coping strategy use in order to assist people with shifts from use of less-effective coping strategies to the use of more constructive or effective coping strategies (Corbin and Strauss 1988; Bodenheimer and Wagner 2002; Battersby et al. 2010).

The broad theoretical foundations described in this sub-section pose a barrier to conducting research into supported self-management interventions. The lack of a clear, theoretical framework for the origins and mediators of self-management make comparisons across studies and choice of outcome measures that reflect change in individual self-management competence problematic. Numerous measures have been proposed over the years as pertinent to self-efficacy, self-regulation and goal achievement (Boger, Demain, and Latter 2013). There is currently no consensus on which measures best reflect these constructs.

Program components

Supported self-management programs have been proposed to build resilience of people affected by long-term health conditions. The key components of supported self-management programs are therapeutic alliance, partnership or collaboration, therapeutic techniques and goal setting (Battersby et al. 2010). Each of these will be described in turn.

Therapeutic alliance is the first key element required in supported self-management intervention programs. A therapeutic relationship can be established between a healthcare practitioner and individuals or whānau (Kazdin 2007). A positive and successful therapeutic relationship ensures that two or more people can work together toward

improving health and wellbeing. It impacts on how well intervention techniques can be delivered (Kazdin 2007). A positive relationship often requires warmth, empathy, caring, genuine regard and competence shown by all participating parties (Beck 2011). A level of trust and willingness to work together indicates a positive working relationship (Kazdin 2007). An effective therapeutic relationship has been found to have positive impacts on health (Schnur and Montgomery 2010). In an Australian qualitative study with cancer survivors, the importance of relationships enabling the survivor to give voice to their experience and be heard by professionals “who took the time to listen and try to understand” was found to be more important than the use of a specific therapeutic technique (MacCormack et al. 2001). Building a therapeutic relationship takes time and attention to relational processes, specifically *whakawhānaungatanga* in the NZ context.

Collaboration is a second key element in supported self-management programs. It is sometimes referred to as goal consensus (Schnur and Montgomery 2010). A meta-analysis of studies exploring the impact of collaboration on psychotherapy outcomes found better outcomes were associated with cooperative relationships and agreement on therapeutic goals (Tryon and Winograd 2011). Collaboration is the basis for person-centred or client-centred interactions using strengths-based approaches (Padesky and Mooney 2012; Sanders and Munford 2010) or motivational interviewing (Miller and Rollnick 2002; Britt et al. 2014; Rollnick, Miller, and Butler 2008). Collaboration is identified as important for cancer survivors because of the need to manage side-effects, comorbidities, and follow-up requiring combinations of medical and self-management (Hack et al. 2005)

Therapeutic techniques, such as cognitive behaviour training or therapy (CBT), are a third key element. These involve use of approaches, such as collaborative problem solving, cognitive restructuring, stress management and guided imagery, to help people evaluate and adapt the way they think about a situation or issue (Beck 2011). These techniques can be delivered by trained counsellors, psychologists, psychotherapists and interventionists in individual or group formats (Padesky and Mooney 2012; Kahl, Winter, and Schweiger 2012; Beck 2011). Several meta-analyses have documented the effectiveness of CBT for people with various medical and psychological conditions (Butler et al. 2006; Hofmann et al. 2012). Studies of CBT with cancer patients have shown benefit for reducing distress and pain (Tatrow and Montgomery 2006; Osborn, Demoncada, and Feuerstein 2006; Hart et al. 2012; Beatty and Koczwara 2010) and addressing fatigue (Quesnel et al. 2003; Campos et al. 2011). In one meta-analysis reviewing studies that utilised CBT techniques with cancer survivors, individual approaches were shown to be

more effective in reducing emotional distress and improving quality of life than group approaches (Osborn, Demoncada, and Feuerstein 2006).

Goal setting is the fourth integral component of supported self-management programs. It is considered vital to enhancing self-efficacy (Locke and Latham 2013; Locke and Latham 2006). The founders of goal-setting theory purport that goals direct attention and effort toward positive action (Locke and Latham 2006). Goal-setting in supported self-management programs are described as person-focused yet developed in a directed fashion in collaboration with the interventionist to address wellbeing. Interventionists foster awareness that goals must reflect lifeworld reality and not be based in judgments on how people should live their lives (Flinders Health Behaviour and Health Research Unit 2012).

Supported self-management programs are complex interventions because they: 1) weave together a tailored set of strategies, 2) are grounded in therapeutic alliance and collaborative problem-solving, 3) incorporate goal-setting, regular monitoring of progress and problems, action planning, and shared decision-making, and 4) promote access to and use of community resources, health system navigation, and effective communication with health professionals. Strategies may be reflected in a tailored care plan (Flinders Health Behaviour and Health Research Unit 2011). Two publications, the 2011 Health Foundation's supported self-management rapid review and the 2010 evidence-based review by Battersby et al., outline key components and principles of these approaches (Battersby et al. 2010; de Silva & Health Foundation 2011). The key components of supported self-management are shown in Figure 8 (de Silva and Health Foundation 2011).

Supported self-management program components found to be useful through rapid review:

- Involving people in decision making
- Emphasising problem solving
- Developing care plans as a partnership between service users and professionals
- Setting goals and following up on the extent to which these are achieved over time
- Promoting healthy lifestyles and educating people about their conditions and how to self-manage
- Motivating people to self-manage using targeted approaches and structured information and support
- Helping people to monitor their symptoms and know when to take appropriate action
- Helping people to manage the social, emotional and physical impacts of their conditions
- Proactive follow-up, and
- Providing opportunities to share and learn from other service users.

Figure 8: Supported self-management program components identified as useful

Source: Health Foundation 2011, 17

The 12 supported self-management program implementation principles are shown in Figure 9 (Battersby et al. 2010).

Supported self-management evidence-based implementation principles:

Multifaceted interventions	Support by diverse providers
Brief targeted assessment	Use of a non-judgmental approach
Collaborative priority and goal setting	Collaborative problem solving
Patient self-efficacy	Active follow-up
Evidence-based information to guide shared decision-making	
Self-management interventions delivered by diverse formats	
Guideline-based case management for selected patients	
Linkages to evidence-based community programs	

Figure 9: Supported self-management program implementation principles

Source: Battersby et al. 2010, 567

In summary, evidence-based supported self-management programs are characterised by four key components: therapeutic alliance, collaboration, therapeutic techniques, and goal

setting. They are complex interventions that utilise assessment processes and can have multiple components and principles embedded in them as exemplified.

Program outcomes

Supported self-management intervention studies have utilised a wide range of outcome indicators. A 2013 systematic review on outcomes of chronic disease self-management interventions identified over 70 different types of outcomes assessed in a subset of 18 studies (Nolte and Osborne 2013). The authors concluded “as evaluations heavily rely on patient self-report, current approaches to program evaluation may not be sufficient to assess the intended impact of self-management” (1805). Accordingly, the overall evidence for the effectiveness of supported self-management intervention programs is described as mixed.

The evidence for effectiveness of self-management intervention for specific conditions, such as asthma (Coster and Norman 2009; Warsi et al. 2012), is more promising compared to evidence generated by reviews of generic self-management programs (Coster and Norman 2009). Most meta-analyses report some positive outcomes of generic self-management support programs, showing small to moderate effect sizes, but with inconsistencies as well (Barlow et al. 2002; Ratima 2009; Chodosh and Morton 2005; Warsi et al. 2012). There have been multiple Cochrane reviews conducted which aim to show effectiveness of supported self-management intervention programs but the results have been inconclusive (Coster and Norman 2009; The Cochrane Collaboration 2008).

It must be mentioned that supported self-management interventions have also been associated with unintended consequences and negative outcomes. One of the earliest published supported self-management studies evaluated an intervention to improve patient question asking during a medical visit. Negative outcomes identified were increased patient anxiety and reduced satisfaction with care (Roter 1977). More recent studies of supported self-management programs suggest that programs may increase inequities (Greenhalgh et al. 2011) and shift the focus from structural drivers and barriers to quality care resulting in further victim blaming (Parkhurst 2013). It is important to consider environmental context and equity at the forefront of intervention protocol development. Although delivery of low-intensity intervention, such as an opt-in supported self-management workshop, may be more straightforward to design and evaluate, this approach may cause unintended consequences by widening the inequity gap between

active information seekers and those that avoid seeking help (Keating 2014). These potential negative outcomes must be considered, assessed, and measured, if possible.

Clinical outcomes are often proposed as intervention effectiveness indicators. In various meta-analyses of the self-management literature, clinical variables measured did not yield consistent positive results across studies (Warsi et al. 2012; Chodosh and Morton 2005; Barlow et al. 2002). Supported self-management programs have been shown to influence some clinical indicators for specific diseases (e.g. asthma, diabetes, chronic obstructive pulmonary disease); however, there has been no clinical evidence of impact for other diseases (e.g. osteoarthritis) (Chodosh and Morton 2005; Warsi et al. 2012; Watson et al. 1997). The evidence for psychosocial and quality of life outcomes was more consistently positive.

A narrative review by renowned self-management researchers Holman and Lorig (2004) identified positive self-perception and improved coping self-efficacy as important outcomes for health. Psychosocial outcomes, such as self-efficacy and resilience, are outcomes that have been commonly measured in association with supported self-management interventions. Individuals affected by chronic disease report being distressed by not coping well with emotional reactions based in anger, fear, frustration and depression (Lorig et al. 2001). Supported self-management has been shown to help people cope with distress by building self-efficacy for coping and developing resilience (de Silva and Health Foundation 2011; Lorig et al. 2001).

QOL is another outcome measure used commonly in supported self-management intervention research. The key meta-analysis that considered QOL outcomes, and not just clinical measures, identified small effect sizes and variable impact on this measure (Barlow et al. 2002). Individual studies of supported self-management intervention tend to show small to medium effects on this measure (Bodenheimer et al. 2002; Howell et al. 2012; van Weert et al. 2008; Watson et al. 1997). However, some studies point out that the underlying constructs measured by QOL instruments might be problematic with decreased sensitivity for measuring how supported self-management impacts on QOL as opposed to the intervention not impacting on QOL (Barlow et al. 2002; Battersby et al. 2010).

Cost-effectiveness indicators have been assessed in supported self-management intervention studies. One common cost-effectiveness outcome measure utilised is reduction in healthcare utilisation (Chodosh and Morton 2005). This outcome measure has been shown to be inconsistently impacted across studies with some studies showing

reductions (Lorig et al. 2001; Wilson 2008) and others finding no change (National Primary Care Research and Development Centre 2007).

Although there is an extensive literature in this area, the choice of outcome measures for supported self-management programs is inconsistent. Evidential reviews have shown that supported self-management intervention can improve key health outcomes for some patients (Warsi et al. 2012; Barlow et al. 2002; Chodosh and Morton 2005; Mccorkle et al. 2011). The literature supports the utility of the approach for delivering modest improvements in health outcomes across conditions but more evidence is needed on key components, applicability of supported self-management interventions for specific populations, as well as use of robust and relevant outcome measures.

Established programs

Supported self-management programs have been delivered over the years by health and supportive care workers, and lay facilitators such as expert patients. They promote the development and renewal of skills and strategies for self-management.

The foundation for these programs is in establishing therapeutic alliance and partnership with the working relationship guided by collaborative priorities for improving health and wellbeing. Cognitive behaviour therapy techniques are commonly associated with supported self-management programs (Richardson et al. 2011). These are often described in association with goal setting (Fisher et al. 2005; Battersby et al. 2010). In most cases, care plans and action plans are an integral part of supported self-management program intervention and these are intended to be routinely monitored and followed up. Most programs aimed to develop a collaborative plan which is intended to be followed up intermittently with health and supportive care workers. A key outcome of interest across programs is identified as self-reported change in perceived self-management competence. Figure 10 presents a schematic representation of key supported self-management intervention program components.

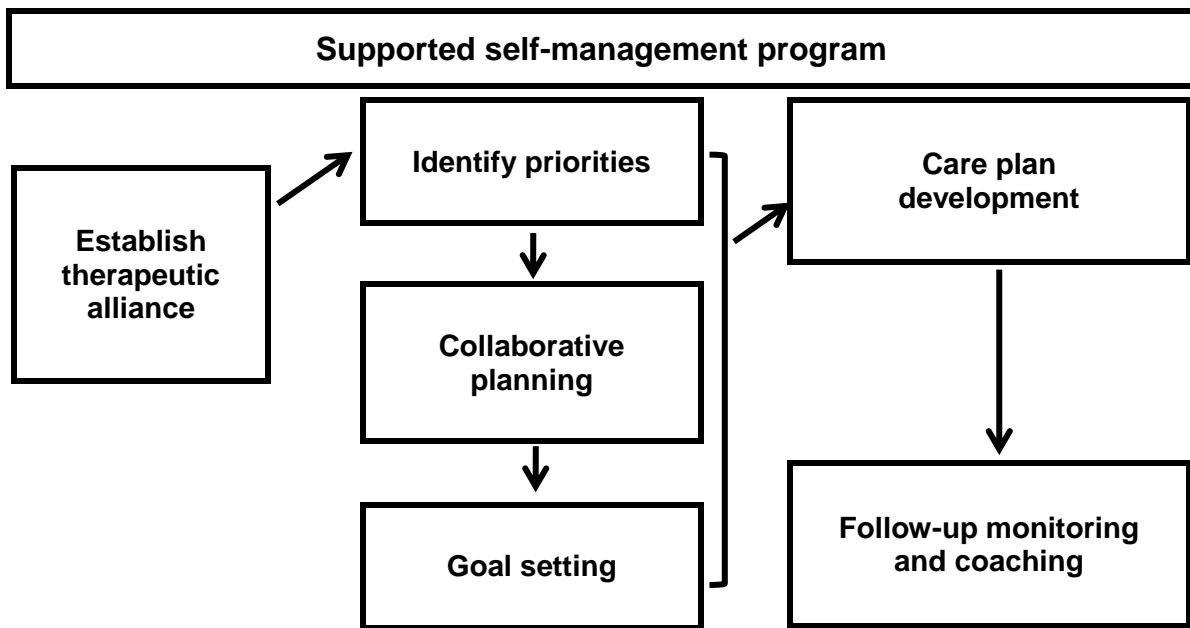


Figure 10: Self-management intervention diagram

There are many supported self-management interventions and programs reported in the literature but most are not well validated and only in use for specific diseases or in specific areas. Therefore, specific programs mentioned in the literature are not all able to be named, described and critiqued in detail in this thesis.

An overview of a selection of the largest established and evaluated programs is shown in Table 5. These programs are classified by mode of intervention delivery, timing, strategies utilised and required facilitator qualifications. The modes of intervention delivery include face-to-face group or individual sessions. Timing is flexible for face-to-face programs but less so for protocol-guided group formats delivered over six or more sessions. Therapeutic techniques range widely. Facilitator qualifications all include training but the facilitator may be a health and supportive care worker or lay-person, depending on the program.

Table 5: A selection of programs described as supported self-management

Supported self-management program title	Mode of intervention delivery	Timing	Therapeutic techniques and strategies	Facilitator qualifications
The Stanford Program (Lorig et al. 2001)	Group	6-7 sessions at 1 per week	Peer support, exercise, relaxation tips, communication techniques, nutrition support	Trained health practitioner and lay-person
The Expert Patients Programme (Wilson 2008)	Group	6-7 sessions at 1 per week	Peer support, exercise, relaxation tips, communication techniques, nutrition support	Lay-person
The Flinders Program (Battersby, Harris, et al. 2010)	One-to-one	Variable	CBT, ACT, Motivational interviewing, coaching, goal setting, written information, action plans, decision support tools, care plans, and e-health online tools	Trained health practitioner or community health worker

From this point forward, this section narrows in focus to the three supported self-management programs shown in Table 5. Because there is such wide variation in delivery, timing and approach within supported self-management programs, only these three generic, well-known, validated and robustly evaluated programs will be described in further detail. These programs are guided by program manuals and all require structured assessments with participants. However, they differ regarding delivery mode, timing, therapeutic techniques used, and facilitator qualifications required. The choice of program for this study was based on a comparison of the differing components of these three supported self-management programs.

The Stanford Program

Kate Lorig and colleagues at Stanford University in the USA developed a program that centred on empowering people to partner with health professionals to improve health outcomes. The seven-week Chronic Disease Self-Management Program (CDSMP) evolved from the Arthritis Self-Management Program. The program, which subsequently became known as the Stanford Program, focused on developing effective healthcare partnerships to support enhanced self-efficacy for people living with chronic conditions. Key components included patient skill-development for problem-solving, and decision-making to include being better able to deal with consequences of chronic diseases within the social environment (Lorig et al. 2001).

The Stanford Program is aimed at enabling, inspiring, and empowering people with chronic conditions to make informed choices and develop strategies to manage their condition. It is facilitated by either two trained health and supportive care workers or by one of these and a person living with chronic conditions themselves. The program is delivered as 'generic', meaning it is open to anyone with one or more self-defined long-term conditions. It is delivered once a week over six weeks in two-and-a-half-hour group sessions. Groups comprise 8-20 participants who range from those recently diagnosed to those managing conditions over the long-term.

The strategies and skills delivered relate to ways people can effectively address common self-management problems and disease-related tasks to manage well day-to-day with the goal being improved health status and lower utilisation of healthcare (Lorig et al. 2001). For example, four ingredients of self-efficacy addressed by the program are task performance mastery, modelling, interpretation of symptoms and social persuasion (Bandura 1977; Holman and Lorig 2004). Based on the principles underlying the program, the course promotes the development of confident and knowledgeable patients who use strategies to manage their conditions effectively.

The first RCT of the program involved over 1,000 people with diagnosed heart disease, lung disease, stroke or arthritis who were followed up for three years (Lorig et al. 1996). The variables evaluated in the trial were health status, healthcare utilisation, self-efficacy and self-management behaviours. Assessments in relation to health status included disability, social/role limitations, pain and physical discomfort, energy/fatigue, shortness of breath, psychological wellbeing/distress, depression, health distress, and self-rated

general health. Healthcare utilisation was measured by recording visits to physicians, visits to the emergency department, hospital stays, and nights in hospital. Patient-reported confidence in behaviours and management were assessed using a self-efficacy measure. Self-management behaviours measured were exercise, cognitive symptom management, mental stress management/relaxation, use of community resources, and communication with physician (Lorig et al. 1996). Program participants, compared to the control group, reported personal health outcome benefits and lower healthcare utilisation rates which persisted for up to three years. There were no differences noted in measures of psychological wellbeing, pain or discomfort (Lorig et al. 2001). An extensive review of the evidence on the Stanford Program, from many studies since that first RCT, was brought together in a meta-analysis focused on supported self-management and its potential for implementation with cancer populations (McCorkle et al. 2011). A more detailed overview of this cancer-specific meta-analysis is presented in the section on supported self-management and cancer survivorship on p. 87. In brief, McCorkle et al.'s 2011 meta-analysis reported that The Stanford Program delivered clinically-significant and improved patient-reported outcomes, in areas such as symptom management and communication. The Program was recommended as a useful way to influence and improve self-management across conditions (McCorkle et al. 2011).

The UK Expert Patients Programme

The Expert Patients Programme was developed in the United Kingdom and is derived from The Stanford Program (Department of Health 2001). The Expert Patients Programme provides support and seeks to foster participants' self-confidence to manage their chronic conditions. Weekly goal setting and action planning are key components of the programme.

The program was established as a lay-led supported self-management program that was intended to inspire and empower people to improve their self-management of chronic disease in partnership with care provided by the National Health Service (Department of Health 2001). The Expert Patients Programme lay-led supported self-management program aimed to inspire the use of strategies and skills to increase agency and confidence related to, what is sometimes termed, the 'expert patient' role (Gao and Yuan 2011; Wilson 2008).

The structure and delivery of the group program is by sessions. It is intended to be delivered once a week over six weeks in two and a half hour group sessions. The course addresses: 1) dealing with pain and tiredness, 2) coping with feelings, 3) relaxation techniques and exercise, 4) healthy eating, 5) communicating with family, friends and health and supportive care workers, and 6) planning for the future (Wilson 2008). It is most often facilitated by a healthcare practitioner and person living with chronic conditions themselves, trained as an expert patient facilitator (Rogers 2001). The program is delivered as 'generic', meaning it is open to anyone with one or more self-defined long-term conditions. Groups comprise 8-20 participants which range from those recently diagnosed to those managing conditions over the long-term. The key difference between the Expert Patients Programme and The Stanford Program is that the former is meant to be led by a trained lay-person living with a chronic condition while the Stanford Program was designed to be led by health and supportive care workers.

The 2001 Expert Patients Programme pilot study trained interested expert patients, defined as people living with a chronic condition, as lay trainers or volunteer tutors (Rogers 2001). The pilot phase enrolled 629 participants who were randomized to an Expert Patients Programme course intervention or control group (National Primary Care Research and Development Centre 2007). The intervention group reported increases in self-efficacy, energy levels and psychological wellbeing; however, no comparative significant improvements were noted for exercise levels or reduction in healthcare utilisation (National Primary Care Research and Development Centre 2007). Although results from the Expert Patients Programme pilot study indicated some small positive effects overall, concerns were raised over its 'fit' with people from vulnerable populations (Rogers 2001). Difficulties with engaging people from ethnic minority groups and areas of high deprivation were noted in the pilot study and were reported to have been subsequently identified in later supported self-management research studies (Rogers 2001; National Primary Care Research and Development Centre 2007). There were no published evaluation reports identified on delivery of this programme within cancer populations specifically.

The Flinders Program

The Flinders Program™ is an evidence-based supported self-management intervention developed in Adelaide, Australia at Flinders University. It is structured around a set of tools for patient-centred assessment, planning and motivational processes (Battersby et al. 2010). It differs from the other two supported self-management programs reviewed here because it is designed to be delivered face-to-face to one individual, but it is flexible enough to incorporate supporters and whānau.

The Flinders Program is designed to be accessed by referral from a healthcare practitioner and can be introduced to anyone with one or more long-term conditions. The program incorporates the Flinders Program standardised tools, namely, the Partners in Health scale, the Cue and Response interview, and the Care Plan. It allows for multiple sessions delivered by a trained healthcare practitioner in one-to-one sessions at clinics, community centres or homes. There is no set time frame outlined for number of sessions or durations of sessions. Although standardised like the Stanford Program, the Flinders Program aims to support patients in a tailored approach that develops confidence so they can manage their conditions effectively.

The Flinders Program originated around the same time as the Stanford Program. It developed as a consequence of the 1997 SA HealthPlus Trial which sought to test whether coordinated care could improve health outcomes (Battersby, 2005). The study found that elements of self-management support were provided based on service coordinator perception of self-management competence rather than on any standardised assessment combined with risk assessment of illness severity or complexity (Battersby 2005; Petkov et al. 2010). The 11-item Partners in Health scale, a standardised assessment tool reflecting self-management competence, was delivered and validated during the SA HealthPlus trial to address this state of affairs (Battersby, Harvey, and Mills 2007; Battersby et al. 2003; Petkov et al. 2010). Evidence from this early intervention study indicated a role for the one-on-one approach to address patient self-management of chronic medical and mental health conditions (FHBHRU 2011). The Flinders Program filled a gap providing a standardised yet tailored approach that was delivered one-to-one and incorporated assessment tools and strategies for self-management skill development.

After further monitoring and development of The Flinders Program, Battersby et al. published an article identifying 12 evidence-based supported self-management

implementation principles (outlined on pg. 69) that were integral to the program (Battersby et al. 2010). A Flinders Program intervention study rationale and functional design was published in 2011 to guide intervention research carried out with the program (Battersby et al. 2010).

The Flinders Program has been widely delivered in Australia. A pre-post study with 176 people managing a variety of chronic conditions found clinically-significant increases in patient-reported self-efficacy as well as decreases in patient-reported pain, fatigue and service usage (Harvey et al. 2008). The Flinders Closing the Gap Program was launched in 2012. It was targeted for Aboriginal and Torres Strait Islander populations and aimed to reduce ethnic disparities in chronic disease care (FHBHRU 2012). In this program, trained community workers acted as facilitators and health navigators (FHBHRU 2012). The Flinders Program strategies and skills helped people with chronic conditions acquire information and practice skills to carry out different medical regimens and lifestyle changes as well as support physical and psychosocial transitions (FHBHRU 2011).

While the Flinders program has not been delivered, or piloted, in the secondary-care setting or hospital-based clinic context, several features of the program's design suggest it may be most appropriate for delivery of acceptable and equitable self-management support in hospital-based cancer clinic settings. The Flinders program is structured to be delivered face-to-face and research indicates this delivery mode achieves better outcomes (Warsi et al. 2012). The individualised delivery mode, rather than group delivery mode, is considered more equitable for delivery in cancer clinical settings because it is less reliant on opt-in. It is also identified to be the preferred mode of intervention delivery for establishing strong relationships, a key priority for Māori whānau-centred cancer care (Slater et al. 2013). Individualised delivery is considered to provide better opportunities for therapeutic alliance and collaboration. The techniques of person-centred goal-setting, action planning and care planning are seen as most appropriate to be delivered face-to-face to assist survivors to build resilience (FHBHRU 2005) .

Program enablers and barriers

Supported self-management program uptake is dependent on many factors at the individual and environmental levels (Bycroft and Tracey 2006). The studies reported on in this thesis aimed to explore the fit of a supported self-management program in the hospital-based cancer setting. Therefore, a review and critique of factors that may act as facilitators or barriers is considered an important addition to the literature review. The individual, interpersonal and environmental factors that may impact on this type of intervention are explored in this section.

Individual level

There is little consistency noted across studies on specific outcomes impacted by supported self-management programs but reviews agree that self-management programs can be beneficial for the individual affected by chronic conditions (Barlow et al. 2002; Chodosh and Morton 2005; Warsi et al. 2012; de Silva and The Health Foundation 2011).

Individual factors that impact on, and also result from, self-management intervention include ability, confidence, motivation and activation of individuals to self-manage (Dixon, Hibbard, and Tusler 2009). In other words, an individual's innate capacity to self-manage impacts on the extent to which self-management programs can be effective (Battersby, 2005; (Dixon, Hibbard, and Tusler 2009). Personal barriers to self-management include low health literacy, lack of motivation, life or health complexity, and lack of capacity to engage with self-management (FHBHRU 2012). Enablers of self-management competence include coping ability and motivation. Coping self-efficacy has been shown to predict more ability to adapt to changing circumstances and uncertainty overall (Bandura 1977).

At the individual level, there is not always a linear progression toward increased self-management competence identified as an intervention outcome (Dixon, Hibbard, and Tusler 2009). A 2009 self-management study found that activation and motivation may be developmental and variable for individual patients (Dixon, Hibbard, and Tusler 2009). In other words, individuals can go through phases on their way to becoming competent and effective self-managers. Further, individuals to whom treatments, medication and advice

are provided within a clinical setting manage in different ways indicating that tailored support fits best with this diversity in management styles (FHBHRU 2011).

It is important to consider unintended consequences. Self-management competence often requires behaviour change which can be a lengthy and challenging process (Mayor 2006). Potential unintended consequences, such as intermittent increases in anxiety, must be considered in the discussion of enablers or barriers to supported self-management program uptake.

Interpersonal level

Interpersonal enablers include health practitioner motivation, delivery style and competency. Health practitioner interest and skill level vary in relation to these competencies. Hibbard et al. (2004) identified that facilitator confidence played a key role in outcomes. There is a clinician toolkit that lists important self-management program facilitator competencies as shown in Figure 11 (Schaefer et al. 2009).

Self-management support strategies described as useful for delivery of these competencies include establishing the person's agenda, active listening, person-centred communication techniques such as motivational interviewing (Britt et al. 2014; Rollnick, Miller, and Butler 2008) and goal setting. The recommendation to clarify facilitator competency to deliver these strategies was emphasised in several self-management program reviews (Ratima 2009; Schaefer et al. 2009). Health and supportive care workers require an interest and willingness to work collaboratively with patients as well as specific skills training to effectively deliver supported self-management programs. Some programs have trainer accreditation requirements.

Supported self-management program facilitator competencies identified:

- Describe and promote self-management by emphasising the patient's central role in managing his/her health
- Include family members at the patient's discretion
- Build a relationship with each patient and family member
- Explore patient's values, preferences, and cultural and personal beliefs
- The patient and providers share information and communicate in a way that meets the patient's and family's needs and preferences
- Collaboratively set goal(s) and develop action plans. Document the patient's confidence in achieving goals, and use skill building and problem-solving strategies that help people identify and overcome barriers to reaching goals
- Provide follow-up on action plans and connect the patient with the community.

Figure 11: Supported self-management program competencies for facilitators

Source: Partnering in self-management support: A toolkit for clinicians by The Institute for Healthcare Improvement (Schaefer et al. 2009, 24)

Environmental level

Environmental factors, such as organisational policies and delivery standards, can be considered enablers or barriers. Health policies increasingly promote person-centred care which is loosely associated with self-management (Ahmad et al. 2014; The Health Foundation 2014). Care coordination is a type of person-centred support in place in NZ to assist patients to navigate the complex system and various support organisations effectively (Blakely 2013; Blakely et al. 2015; Collinson et al. 2013). Navigating system complexity can overwhelm finite self-management resource and capacity. Provision of care coordination can be considered an enabler of self-management.

Overarching structural factors are another type of environmental impact that may enable or block self-management. Structural factors include access to care (Cormack et al. 2005; Rumball-Smith 2009) and variability in care (Cunningham, Triggs, and Te Hoe Nuku Roa Research Team, 2014). Cancer care is most often delivered across specialised areas (i.e. surgical, oncology, radiation oncology). This differs from care for other conditions which are often less siloed and less complex to navigate. The structure of cancer care is a barrier to timely, accessible care and challenges exist in coordination across specialist areas (Levit et al. 2013; Minister of Health 2003b; Ministry of Health 2010b).

Another environmental factor at the structural level relates to equity. The evidence of effectiveness of supported self-management programs for populations experiencing

inequities in healthcare is minimal (Lawn et al. 2007; Greenhalgh et al. 2011). According to Greenhalgh et al. (2011) “no model of self-management education or peer support has yet achieved widespread reach and acceptability with minority ethnic groups” (Greenhalgh et al. 2011, 28). There is limited evidence for the effectiveness of self-management interventions in indigenous populations (FHBHRU 2012) which indicates a knowledge and practice gap, but, more importantly, raises concerns about whether these types of programs may contribute to a widening gap in inequities (Ratima 2009) at the structural level in NZ healthcare organisations.

Criteria identified to inform program choice

This section aims to identify criteria for best choice of a supported self-management intervention program to pilot with cancer survivors in NZ. There were three programs considered. The criteria were developed considering evidence, equity and feasibility variables within the cancer context. Specifically, the selection criteria were related to program: 1) standardisation and structure to ensure fidelity, 2) adaptability for tailoring across conditions and populations, 3) facilitator requirements for professionalism and accreditation to build referral confidence, 4) delivery, with emphasis on one-on-one delivery that could involve whānau, and 5) environmental context and structural barriers considered.

The three main programs described in this chapter were compared against the criteria. Table 6 displays the comparative results. The Flinders Program was identified to be the best fit because it met the most points identified in the criteria. It was standardised yet could be tailored, required delivery by accredited practitioners, and had the most flexible delivery options in that it could be delivered one-on-one during standard hospital appointments with participation of whānau.

Table 6: Comparing three supported self-management programs using selection criteria

Structured supported self-management programs	Tailored (Yes/No)	Facilitator accreditation required (Yes/No)	Accommodated one-on-one delivery and whānau (Yes/No)	Flexible delivery suited to clinical settings (Yes/No)
The Stanford Program (Lorig et al. 2001)	No	Yes	No	No
The Expert Patients Programme (Wilson 2008)	No	Yes	No	No
The Flinders Program (Battersby et al. 2010)	Yes	Yes	Yes	Yes

The Flinders Program is a high-intensity supported self-management intervention. In other words, it is delivered face-to-face and requires a comparatively higher level of time investment than the other programs it was compared against. Nevertheless, this high intensity program was indicated, based on the criteria, as the most equitable and effective approach to explore.

Supported self-management: the NZ context

In this section, the limited research on supported self-management programs in NZ is reviewed.

Supported self-management in NZ's healthcare system

Supported self-management programs emerged in NZ primary care settings in the 1980s. Disease-specific supported self-management programs have been administered and evaluated in the areas of diabetes, asthma, heart failure and other long-term conditions (Beasley et al. 1989; Counties Manukau DHB 2016.; D'Souza et al. 1994; Ritzema et al. 2010; Steinsbekk et al. 2012; Watson et al. 1997). NZ literature describing self-management programs have suggested that they can reduce healthcare practitioner dependency (Counties Manukau DHB 2016; D'Souza et al. 1994; Town et al. 1995) as

well as increase self-determination and wellbeing for those affected by chronic conditions (Pere, 2005). According to Pere (2005), supported self-management is needed to establish control over long-term conditions such as diabetes. She described the support for patient self-management by health and supportive care workers as a “pre-requisite for self-determination, and self-determination as a precursor for wellness”, particularly for Māori and other indigenous peoples residing in NZ (111).

It has been shown that a shift from disease-specific patient education-based self-management programs to non-disease specific problem-solving based supported self-management has been occurring in NZ since the year 2000 (Ratima 2009). The delivery of supported self-management programs has varied widely across the country. Variations have occurred in relation to program delivery context (i.e. primary care or secondary care environments), disease-focus, and populations targeted.

The 2008 ABCC study was a major cross-condition national study that promoted supported self-management. The series of studies conducted under the auspices of ABCC aimed to describe chronic condition management practice in primary care settings across NZ. The study series was comprised of literature reviews and a stocktake of chronic condition management healthcare practice. Overall, the study findings pointed to national variability in chronic condition management practices (Connolly et al. 2009; Connolly et al. 2011), persistent inequities in healthcare delivery (Sheridan et al. 2011) and underdevelopment of best practice, particularly with regard to delivery of supported self-management intervention (Connolly et al. 2009). Healthcare practitioners stated that self-management approaches were hard to deliver because they required gaining deeper insights into health behaviours, and this approach was not supported by funding models and the national data focus on clinical management (Connolly et al. 2008).

The 2008 ABCC study cited minimal development and integration of supported self-management initiatives into health delivery across NZ primary care practice (Connolly et al. 2009). The study authors concluded that there was a lack of conceptual understanding of best-practice chronic condition management in NZ (Connolly et al. 2008). The study recommended building and monitoring a systematic structure nationally (i.e. guidelines), funding initiatives to train the trainers (especially lay people), community/whānau engagement, and financial support (Connolly et al. 2009) to progress supported self-management integration.

In 2009, Ratima conducted a narrative review of supported self-management in NZ with a focus on applicability for Māori health delivery. This review provided further support for these types of interventions but identified the complexity of delivering them effectively. Ratima (2009) provided an insightful analysis of the self-management literature base and the barriers and enablers for Māori. A key issue identified was methodological limitations of published research. This issue was named as a barrier to drawing out specific success factors and assessing outcomes. Barriers identified with regard to delivery of supported self-management for Māori included lack of community/whānau engagement, unclear training requirements for facilitators and perceived lack of intervention tailoring to address personal priorities, values and goals (Ratima 2009).

There were two NZ evaluations of The Flinders Program published in 2010 (Horsburgh and Bycroft 2010; Horsburgh et al. 2010). In one study, results of a survey sent to the 500 NZ-based health professionals who had completed Flinders training since 2005 were reported. Of the 152 Flinders trained respondents, most reported that they did not use the program routinely in clinical practice (Horsburgh and Bycroft 2010). Organisational barriers and lack of buy-in were identified as the biggest barriers to wider program implementation in primary care settings (Horsburgh and Bycroft 2010).

The second NZ-based evaluation of the Flinders Program described NZ-specific system and organisational barriers as detrimental to the delivery of the program in primary care settings. Funding models were highlighted as the biggest barrier to intervention delivery. However, in addition, time-bound appointments were also identified as a barrier because they did not allow for effective delivery of conversation-based supported self-management initiatives (Horsburgh et al. 2010). The findings from these two studies aligned and indicated low levels of Flinders Program delivery in NZ (Horsburgh et al. 2010).

Although program delivery was problematic, the researchers suggest the program is useful, needed and appropriate because it helps support patients to address the biggest issues of importance to them first (Bycroft and Boyd 2011). These issues, whether related to financial, housing, social and emotional areas, are often so overwhelming that health concerns became a lower priority than what health providers expect (Bycroft and Boyd 2011). Two Primary Health Organisations, Te Hononga and Manaia, reported that they successfully use the Flinders Program for assessment and care planning for their patients with long-term conditions (Bycroft and Boyd 2011).

Efforts continue to support delivery of self-management approaches. In 2011, Health Navigator NZ published a supported self-management toolkit (Bycroft and Boyd 2011). Health Navigator NZ is an Auckland-based non-profit that continues to support health and supportive care workers and interested public through a dedicated website gateway for health management resources (Bycroft and Boyd 2011). The toolkit contained assessment tools, action plans and goal-setting worksheets as well as care plan suggestions. It has not been formally evaluated.

To date, there have been no published studies of supported self-management intervention programs conducted in cancer care settings in NZ.

Supported self-management and Māori

The fit and impact of supported self-management programs with indigenous populations internationally is questionable (Greenhalgh et al. 2011). The majority of published supported self-management program studies have been carried out with predominantly white, middle-class, and female participants (Wilson 2008; Newbould, Taylor, and Bury 2006; Thoolen et al. 2010; Mills et al. 2014). This indicates a predisposition to participate in research by people from these demographic groups likely resulting in increased self-management skill among this group. There is a risk that inequities can increase if supported self-management programs have differential uptake between demographic groups.

Mills et al. (2014) published a review of self-management programs for disadvantaged populations living with chronic conditions. The evidence shows that disadvantaged populations have higher rates of chronic conditions and worse outcomes but "have less access, lower rates of participation and much higher rates of attrition in self-management programs than other less vulnerable and affluent groups" (Mills et al. 2014, 1). This raises an important consideration for intervention implementation. It also signals the need for more research into the underlying causal mechanisms associated with this type of intervention. Since 2014, Mills and other collaborators have published a concept map and frameworks to inform supported self-management program development and delivery that is inclusive of disadvantaged populations (Mills, Bergeron, and Perez 2015; Mills et al. 2016).

There have been no published data on the actual delivery of supported self-management programs specifically with Māori. Yet, as previously described, a key consideration for NZ health policy is engagement and partnership with the indigenous Māori population to reduce inequities. Ratima's 2009 narrative review focused on whether supported self-management approaches could be integrated into Māori whānau-centred care as a way to address differential access to care (Ratima 2009). Ratima's review report emphasised cultural relevance for intervention delivery. However, the review failed to consider the widely differing categories of programs described in the literature under supported self-management terminology. Although the review was not intended to be systematic, it would have been more useful if it had described the different approaches that comprise the use of this terminology and how the various components of supported self-management fit with the Māori philosophies of health. Ratima recommended further research with Māori in light of the potential for supported self-management to support self-determination in health (Ratima 2009).

One of the aims of this study was to specifically investigate the acceptability and feasibility of this program in cancer care with Māori. In considering Ratima's (2009) and others recommendations (Connolly et al. 2009; Horsburgh and Bycroft 2010; Horsburgh et al. 2010; Mills et al. 2014), The Flinders Program seemed to be the best fit for Māori in terms of potential for cultural fit and whānau inclusion because it emphasised relationship building through face-to-face delivery, could be tailored to incorporate all aspects of Te Whare Tapa Wha and was able to be responsive to context.

Supported self-management for cancer survivors: the international literature

Supported self-management programs have been delivered to people managing various long-term conditions over the last 20 years. Although contemporary supported self-management programs more often take a generic, non-disease specific or cross condition approach, it seemed useful in this thesis to focus on the cancer-specific literature to help identify if this approach had been applied in the cancer setting. Many studies were identified. As per the previous approach, the review process focused on meta-analyses first and then prioritised relevance to supported self-management programs delivered in similar health care settings to NZ.

McCorkle et al. (2012) published a meta-analysis of supported self-management across the cancer control continuum. The study defined cancer self-management as “those tasks that individuals undertake to deal with the medical, role, and emotional management of their health condition(s)” (McCorkle et al. 2011, 51) and identified 32 published cancer-specific supported self-management intervention studies from 1992 onward. They limited their review to the 16 studies that were randomised, described the intervention and reported phase of treatment. Each study showed modest improvement in at least one outcome of interest. However, the reported outcomes varied between studies with individual outcome improvements shown most notably in pain coping self-efficacy, quality of life and reducing healthcare costs. The authors concluded that cancer trajectory stages were critical components of supported self-management outcome with interventions in the cancer context occurring differentially during active treatment, across different modalities and during the post-treatment transitional survivorship time period. The review concluded that this approach was on the rise and that improved outcomes were selectively indicated in various domains during treatment (McCorkle et al. 2011).

Although no NZ studies were found, one evidential review of self-management had been published in Australia (Ugalde et al. 2015). This review was based on 15 studies. One study reviewed piloted delivery of an adapted Stanford Program for cancer survivors in South Australia (Beckmann et al. 2007). An intervention group participated in the adapted program while a control group undertook the original program. The 29 cancer survivor participants preferred the cancer-specific adapted program while caregivers preferred the original program. In another study, the Taking CHARGE program was delivered to twenty-five women (Cimprich et al. 2005). The program involved four contacts with a nurse or health educator over a seven-week period constituting two group meetings and two telephone sessions. Women reported that the program was useful and they felt that the self-management strategies gained would be useful for coping with concerns in the future (Cimprich et al. 2005).

In 2013, Paula Howell conducted an unpublished study in Melbourne, Australia targeting transitional survivorship in cancer survivors (P. Howell, personal communication, November 24, 2013). This study implemented a shared care model for survivorship care between a cancer centre and cancer non-government organisation. At the end of a treatment phase, patients were referred to the project by their healthcare practitioner. The Cancer Council Victoria Helpline cancer information nurses were the project interventionists. Each project nurse was trained in motivational interviewing and goal

setting. The nurses called the participants up to 12 times and collaboratively worked to develop a health and wellbeing plan with personalised goals established. Common themes for wellbeing goals set by the participants included holiday planning, exercise, dietary changes, managing challenging emotions including fear of recurrence or depressive symptoms, managing a difficult relationship, and return to work. Follow-up assessment calls were scheduled for one, four and eight months post-treatment. Clinically significant changes were noted over time in the domains of positive engagement in life ($p=0.01$), emotional wellbeing ($p=0.02$) and health literacy ($p=0.006$). An overview of results, enablers and barriers from this and five other two-year cancer survivorship demonstration projects was published in 2015 by Jefford and colleagues (Jefford et al. 2015). Strong clinical leadership was identified as a critical success factor across all six demonstration projects (Jefford et al. 2015).

An additional literature search was conducted to narrow the findings. The terms 'colorectal cancer' and 'bowel cancer' or 'neoplasms' in addition to the search term 'self-management' were utilised. Most resulting abstracts, after being scanned, only mentioned the term 'colorectal cancer' but were not targeted for this cohort. After further review, 18 colorectal cancer and self-management studies were identified for in-depth critical analysis. Quantitative, qualitative and mixed methods approaches were reported and reviewed in these studies with a colorectal cancer cohort. Appendix A provides a summary of each of these studies.

Across the 18 colorectal cancer self-management studies identified, the majority of the studies used qualitative methodologies: interviews and focus groups. Most interviews took place with participants during a post-surgical treatment phase of colorectal cancer treatment. Studies were of mainly low quality with small numbers of participants and minimal analyses undertaken.

Colorectal cancer impacts on quality of life were described in these studies; especially for those who were younger, women, those who have had right hemicolectomy surgery and those who experienced higher diarrhoeal distress. In general, the main outcome measure utilised was QOL with results indicating low mental health satisfaction across the board (Pan and Tsai 2012).

Necessary adjustment was a key theme that emerged from the qualitative studies. Adjustment was needed to accept the reality of the cancer diagnosis, survive cancer and move forward post-treatment, and cope with lingering side-effects. This theme was

eloquently summed up by a Swedish qualitative study as ‘Life is back to normal and yet not’ (Ohlsson-Nevo et al. 2012). Despite barriers to self-management reported by some colorectal cancer survivors, such as ostomy limitations and fatigue, survivors described being motivated to engage in health-promoting behaviours (Ganz, Casillas, and Hahn 2008; Hewitt, Greenfield, and Stoval 2006).

Gaps in survivorship care were specifically noted in two of the studies. A UK-based qualitative study with 27 colorectal cancer survivor participants reported that participants felt they were left to cope alone at home once immediate and acute symptom management was no longer needed. This reflected a gap in post-treatment survivorship care (Beaver et al. 2010). In an Australian study, colorectal cancer patients reported that they wanted lifestyle and psychosocial care advice from health practitioners, however, Australian health and supportive care workers who participated reported that they were most comfortable stating facts and were not in agreement about the need for providing patients with lifestyle and psychosocial care advice or information about side-effects and self-management (Baravelli et al. 2009). These studies both indicated the need for survivorship support for colorectal cancer survivors.

In a qualitative study from Canada, participants stated that the unexpected long-term duration of side-effects led to colorectal cancer survivorship uncertainty and stress (Galloway and Graydon 1996). This represented a mismatch in expectations and created a communication gap between survivors, and health and supportive care workers.

These studies indicate that research evaluating supported self-management programs in the cancer context was needed to address perceived gaps in survivorship care (Beaver et al. 2010; Baravelli et al. 2009) and mismatched expectations between patients, and health and supportive care workers (Institute of Medicine and Committee on Quality of Health Care in America 2001; Jefford et al. 2008; Weeks et al. 2012). A further study recommended that supported self-management intervention needed to “focus on helping patients accept their disease, and then learn how to live with cancer and its various ramifications” (Chao et al. 2010, 2279) as well as enhance perceived self-control over managing side-effects (Kidd et al. 2008). Although the colorectal cancer care management role was often reported as shared between the individual diagnosed with cancer and their partner or whānau, supported by health and supportive care workers, coping styles and self-management were described in different ways by these various supporters (Ohlsson-Nevo et al. 2012).

Of the reviewed colorectal cancer-specific intervention studies, only one published RCT was of good quality and fit. It applied the same definition of supported self-management utilised in this thesis. The 2008 two-armed prospective study by Hawkes et al. in Australia involved 410 people being treated with chemotherapy for colorectal cancer. The intervention group received individual self-management promotion consisting of 11 telephone coaching sessions based in Acceptance and Commitment Therapy delivered over a six-month period. The health coaching sessions were delivered by accredited health coaches guided by a custom developed web-based computer application used to enhance positive lifestyle behaviours. Hawkes et al. proposed that “interventions to improve quality of life after colorectal cancer may be most effective if they target symptom management, psychosocial and lifestyle variables, or health behaviours, in a comprehensive and integrated approach” (Hawkes et al. 2009, 2). The study did not enable inclusion of family or whānau in intervention delivery. The researchers found the low-intensity telephone-based self-management intervention to be effective for improving physical activity, dietary habits, and body mass index in colorectal cancer survivors but not quality of life. The authors concluded the supported self-management telephone-based intervention was convenient, low-cost, feasible and improved some important health outcomes (Hawkes et al. 2013).

Summary

This chapter presents the results of a literature review on supported self-management to inform selection of an appropriate intervention program to trial in the NZ context. Supported self-management program intervention is a promising approach to address survivorship impacts faced by cancer survivors.

The studies identified under the supported self-management search strategy were found to be diverse due to heterogeneity of study populations and differing interpretations of supported self-management. The narrative review presented here prioritised meta-analyses and studies that reflected the aims of this research. The aims of this research were to generate NZ-specific information on the acceptability and feasibility of a supported self-management intervention program in the hospital-based cancer setting.

Many of the early published trials of supported self-management were carried out with people managing specific chronic conditions. Meta-analyses of these supported self-management intervention studies identified some positive outcomes in quality of life and

clinical parameters. Various outcome measures were utilised but there has been no consensus on the most appropriate outcomes measures for use.

Justification for conducting the phase one and two studies presented in this thesis was provided by foundational work and recommendations in published papers, particularly informative were publications by Jefford et al. and Sarfati et al. These authors have suggested that more research is needed into self-management approaches for cancer survivors. They further suggest that lack of hard data on intervention mechanisms and specific outcomes should not preclude preliminary and exploratory studies into novel approaches that may improve health outcomes.

Contemporary supported self-management programs have multi-pronged theoretical foundations and incorporate four key components: therapeutic alliance, collaboration, therapeutic techniques and goal setting. There are three well-known programs internationally: The Stanford Program, The UK Expert Patients Program and The Flinders Program. Through each of these programs, health and supportive care workers partner with people affected by chronic conditions to identify problems or issues, problem-solve, and share in decision-making across an array of possible actions in the face of changing life and health circumstances.

The Flinders Program was identified as the program of choice because it most closely matched the criteria developed from the literature. It was structured yet enabled tailoring. It was intended to be delivered by accredited practitioners to individuals or whānau. It was flexible. It incorporated standardised assessment processes and various strategies and tools that could fit with the hospital-setting.

To date, there have been no published studies of The Flinders Program conducted with a colorectal cancer-specific population internationally, nor with the general cancer population in NZ. This research can address these gaps and explore the acceptability and feasibility of The Flinders Program with Māori and non-Māori cancer survivors. Cultural relevance and acceptability for Māori is a priority consideration in light of inequities. Timing, setting and mode of delivery are also important considerations with no evidence available on these parameters of effective intervention delivery with cancer populations in NZ. More research is needed.

CHAPTER 4: Phase one qualitative study

E mohiotia ana a waho kei roto he aha

One cannot know from the outside what is contained within

The overall purpose of the two-phase study reported in this thesis is to document impacts of cancer survivorship and inform equitable redesign of care pathways for cancer survivors. If the phase one data provides evidence that progression to a phase two study is warranted, a quantitative feasibility study is envisioned.

This chapter describes the phase one methods and results. It reports on survivors' and health professionals' cancer experiences and views. The subset of research questions addressed in this first phase of the study are:

1. What are cancer impacts and how are they experienced by survivors in NZ?
2. What other factors contributed to life and health complexity, and coping for NZ cancer survivors?
3. Can a supported self-management intervention help address cancer and complexity impacts for survivors?

The aims were to:

- A. Qualitatively explore, with survivors and health professionals, cancer treatment impacts, life and health complexity, as well as management strategies utilised by NZ cancer survivors during and post-treatment; and,
- B. Use an intervention vignette to gauge the perceived acceptability of The Flinders Program, a supported self-management intervention program, in the NZ hospital-based cancer clinical setting.

The research presented in this thesis follows the flow of the MRC complex intervention framework. This chapter and the next one are presented as stand-alone chapters in order to assist the reader in following the flow of study phases. This chapter contains the rationale, methods, results and discussion for the first phase of the research, a qualitative modelling study. The next chapter is a stand-alone chapter describing a phase two quantitative exploratory study. Combined findings are discussed in Chapter six.

Rationale

This first section presents the rationale for the phase one qualitative modelling study. In this study, the experience of cancer impact was explored with cancer survivors and health professionals.

Qualitative research is carried out using systematic processes to explore human experiences, behaviour and perceptions. By exploring the experiences and views of cancer survivors and health professionals, this study aimed to describe cancer impacts, management strategies and the acceptability of The Flinders Program as a Chronic Care Model-affiliated supported self-management intervention to improve cancer care. The data represents a snapshot of NZ survivors' and health professionals' experiences and views. It can be used to indicate if a new approach is generally acceptable or outright rejected.

Consideration was given to the best qualitative approach to use to address the aims of the study. Qualitative approaches considered included Grounded Theory, Interpretive Phenomenological Analysis and Framework Analysis. A Thematic Analysis or Content Analysis, incorporating Framework Analysis, was considered the best approach (Denzin and Lincoln 2005). A Thematic Analysis develops themes based on commonalities and differences in qualitative data in order to draw descriptive conclusions clustered around themes (Gale et al. 2013). The addition of a Framework Analysis approach incorporated a foundational fore structure to help identify commonalities identified from existing evidence (Gale et al. 2013). Framework Analysis has been used extensively in healthcare research and is characterised by focusing on specific questions, a priori issues and working in limited time frames (Srivastava and Thomson 2009). Framework Analysis builds a frame into thematic analyses (Ritchie and Spencer 1994). The key ideas that form the foundational frame are derived from existing theories and philosophies. The frames chosen were based on a key guiding principle identified for this study; a person-centred rather than disease-centred focus as presented in the Te Whare Tapa Wha model (Durie 1994). The impact data is structured according to the four cornerstones of wellbeing: physical, emotional, social and spiritual health (Durie 1994).

Klimmek & Wenzel's (2012) adapted cancer survivorship framework was used as the frame for the analysis of self-management strategies. There was no specific Māori-centred survivorship framework available to draw on related to this concept. Klimmek & Wenzel's (2012) survivorship framework outlined work in three areas: illness-related work,

biographical work, and everyday life work. Illness-related work, as applied to cancer survivorship, related to managing symptoms, disability or loss of function, diagnostics and ongoing surveillance, crisis prevention and handling, as well as care-planning and maintaining the continuum of care. Biographical work included contextualizing (i.e. making the illness part of ongoing life), coming to terms with illness consequences and one's own mortality, restructuring one's self-concept, and recasting one's biography in to the future. Everyday life work related to day-to-day tasks of cancer survivors including household and relationship maintenance as well as management of stress and emotion. The Adapted Illness Trajectory Framework enabled a structure to assign the many types of visible and invisible tasks involved in cancer survivorship (Klimmek and Wenzel, 2012, e501).

Perceptions and views on supported self-management were derived from a vignette approach and results presented in a holistic frame which described the individual and environmental determinants identified. According to Hoddinott et al. (2013), intervention vignettes can be a useful approach to model acceptability of proposed approaches with the target audience.

Methods

In this section, interview guide development, stakeholder recruitment, as well as focus group and interview processes, are described. Prior to protocol development, consultation on the study rationale as well as the focus group and interview approach was conducted with Māori leaders and regional representatives from Capital & Coast District Health Board. Māori consultation with the C3 study advisory group, Otago University Ngai Tahu advisory board and the Capital & Coast Research Advisory Group – Māori was informative. Approvals to proceed were provided. These groups were regularly kept up to date on the study protocol development. Once the protocol and accompanying information sheets, consent forms and discussion guides were developed, an expedited application was submitted to the Central Health & Disability Ethics Committee. This was the first application submitted using the now standard electronic system. Approval was granted in October 2012.

Interviews and focus groups were proposed as a way identify any gaps in survivorship care and inform the acceptability of The Flinders Program. Focus groups were comprised of cancer survivors residing in the lower North Island of NZ, specifically the greater

Wellington and Palmerston North regions. Interviews were held with key informant health and supportive care workers working in the same parts of NZ.

Ethical considerations were prioritised. These included ensuring informed and voluntary consent, confidentiality and minimisations of risk.

Informed and voluntary consent was both described and affirmed in writing. All research participants were provided with an information sheet describing the purpose and conduct of the study. Each participant was asked to sign a consent form which also included demographic questions on gender, age, and ethnicity (see Appendices C and E). It was confirmed that participation was voluntary and that potential participants could withdraw participation and data at any time.

Confidentiality processes and practices were applied. All data were stored securely in locked filing cabinets or password-protected computer files. All identifying information was removed from the transcripts and codes used instead.

Options for minimisations of risk were addressed prior to the start of the sessions. Participants were informed that the topics or conversations might cause distress because of the sensitive or difficult nature of their personal experience with the subject. Options were provided for follow-up to reduce any distress participants might experience as a result of the focus groups or key informant interview sessions.

A focus group discussion guide (see Appendix D) and an interview guide (see Appendix F) were developed to facilitate conversations around cancer impact and perceived gaps in cancer care, self-management strategies and supported self-management intervention with research participants. The development of the guides was informed by the literature that showed that cancer impacts on survivors' abilities to self-manage (see literature review chapter 3). Simple, yet targeted, questions were included to assist the facilitator to structure the sessions or interviews. Questions posed through focus groups and key informant interviews reflected the objectives of the study. Questions around cancer impact and self-management strategies were asked first in order to set the scene for the introduction of the supported self-management vignette. The vignette, as a qualitative tool, was utilised to introduce the concept of supported self-management as an intervention. This enabled the facilitator to talk people through the potential intervention and gain different perspectives on the concept and its acceptability.

A mix of indigenous and non-indigenous New Zealanders was purposefully sought to participate in focus groups held in the greater Wellington region and Palmerston North. Both men and women were invited to participate. Survivor perspectives on the impacts of their cancer experience and the perceived acceptability of the intervention were explored.

The opportunity to participate in key informant interviews was offered to people who work professionally with people affected by cancer. A discussion guide provided the template for the exploration of supported self-management and care planning in the NZ hospital-based cancer care context (see Appendix F). Key stakeholders were asked about perceived intervention acceptability and feasibility as well as insights into intervention timing, setting and delivery.

Focus groups

The primary eligibility criteria for participants was a previous colorectal cancer diagnosis and receipt of treatment for cancer (see Figure 12).

Eligibility criteria for study

- Acknowledged primary cancer diagnosis, particularly colorectal cancer, with receipt of surgery or adjuvant chemotherapy treatment;
- No apparent or reported physical or mental distress that would deem the trial to be overly burdensome;
- No apparent or reported impaired ability to comprehend the intervention;
- No history of taking part in Flinders or lay-led self-management programs
- Normally resident in NZ.

Figure 12: Phase one focus group eligibility criteria

Focus group participants were purposively recruited and self-selected through project advisors, recruitment flyers and an advertisement in CanTalk, the Cancer Society newsletter. Potential participants were encouraged to contact the study lead via telephone, email or through Cancer Society staff. The study lead followed up to explain the study and to identify best days/times for the focus groups. Monetary incentives (\$30) were offered as a contribution toward time and travel expenses.

Best practice focus group methods were reviewed and applied (Liamputtong 2011; Denzin and Lincoln 2005; Patton 2002). The participants were linked by eligibility criteria that

encouraged shared experiences of cancer diagnosis and treatment. The co-facilitators prioritised interchange among participants, and sessions lasted for an established length of time (Denzin and Lincoln 2005). Each focus group was limited to about 1.5 hours and was co-facilitated by an experienced qualitative research team, including the author of this thesis. Participants were asked to draw on their social context and lived experiences of cancer in response to questions asked. The forum was designed to promote cultural and emotional safety during the sessions.

Principles of Kaupapa Māori research methodology were explored to help inform the phase one research. Kaupapa Māori research methodology is underpinned by principles of tika (authenticity) and pono (truth) and the values of manaaki (show respect) and tautoko (support) which are important to tikanga Māori (Mead 2003). As a non-Maori, I was not able to apply Kaupapa Maori research methodology, however, examining the approach helped in my attempts to provide a culturally safe research experience for Māori participants. Smith (2012) recommends seven intervention elements to guide good Kaupapa Māori research practice (see Figure 13).

Seven practices to guide Kaupapa Māori research

Aroha ki te tangata – to show respect towards people. This can be done through emphasis on whakawhānaungatanga to establish links through conversations

Kanohi ki te kanohi – face-to-face conversations shows respect and authenticity

Titiro, whakarongo, korero – look/watch, listen, then speak

Manaaki ki te tangata – to care for

Kia tupato – to be careful

Accountability to Maori participants

Kaua e takahia te mana o te tangata – do not stamp/trample on

Kaua e māhaki – to be humble

Figure 13: Seven components of Kaupapa Māori research

Source: Smith 2012

A Māori-specific focus group was envisioned. Guidance was sought from Māori study advisor, Pauline Wharerau, and researchers at the Te Rōpū Rangahau Hauora a Eru Pōmare based at Otago University Wellington. It was suggested that a Māori researcher work with me to conduct the Māori-specific focus group so to best deliver empowering, culturally safe research practice in line with Kaupapa Māori research principles.

Key informant interviews

Potential participants were approached if they were identified as providers of cancer care or associated services. Health professionals were recruited based on project advisor advice, personal knowledge, and snowball recommendations from interviewees. The health professionals approached included cancer specialists, generalists, clinical nurse specialists, community nurses, information nurses, and social workers.

Potential participants were initially contacted through an email containing a project brief and request for 30-minutes of their time to discuss their views on the intervention. The author followed up with each contact to explain about the study, identify best days/times for the interviews, and record contact details so an information sheet could be sent out (see Appendix E). Interviews were conducted face-to-face or by telephone with consenting health practitioners. Topics raised included views on supporting patients with life impacts of cancer and the possible role of supported self-management intervention in the hospital setting. Key informants who participated in interviews were not provided monetary incentives.

The interviews were carried out to gain insights into the particular constraints and opportunities afforded by those working in or alongside NZ cancer care settings. Health and supportive care workers were asked their views on perceived gaps in cancer care. They were also asked about self-management strategies patients used and their views on the acceptability of a supported self-management and care planning intervention (e.g. The Flinders Program) delivered in cancer clinic settings.

Data handling

There are multiple steps to data handling within a Framework Analysis (Patton 2002). In this study, the steps included data familiarisation, indexing, identifying a thematic frame, charting and interpretation. In undertaking this framework analysis, audio-recorded data were transcribed from focus groups and key informant interviews. These data were subject to iterative review to achieve data familiarisation. The detailed facilitator and interviewer notes from the sessions were concurrently reviewed. Data were then openly coded. Each code consisted of words or phrases. The codes were then indexed, grouped and categorised. These codes were reviewed and cross checked by a study supervisor (LS).

The index developed from data was embedded into the foundational frame. The data were interpreted deductively to identify key themes. This analysis was cross-checked by the study supervisor (LS), discussed with the author, and amended as appropriate once consensus was reached.

Data from the Māori-specific focus group were considered first to inform the foundational interpretations of the full data set. This approach aimed to prioritise Māori views as a guide to frame experiences and assessment of intervention acceptability.

In each thematic section, the focus group and key informant interview data were illustrated by indicative quotes. The quotes were used to illustrate the groups' view or an individual view. At times, an interpretation on how the quote related to the theme was included. For reasons of anonymity, safety and best-practice, comments made by participants in the focus groups were not individually identified (Liamputtong 2011). In contrast, the key informant interview quotes were kept confidential but identified by a non-representative alpha-numerical combination corresponding to each specific key informant. The full results informed whether progression into the next phase of the intervention framework, namely a phase two pilot study, was indicated.

Participants

Thirty-six people participated in phase one: 24 in focus groups and 12 in interviews conducted between October 2011 and March 2012.

One focus group (n=6) was comprised solely of people who identify as Māori. This was purposefully organised in an attempt to provide a cultural safe setting for the research participants.

The other focus group (n=18) can be described as multicultural. This was a larger than expected group but it was deemed important not to turn anyone away that showed up. There is no gold-standard focus group number but most are reported to have between 7-15 participants (Liamputtong 2011). Participants in the multicultural focus group ranged in age from 36-73 years (average age = 55) with two-thirds of each group being female participants (n=17). Life roles varied amongst participants. For example, there was a mix of people employed, part- and full-time, and retired.

Key informants (n=12) included a social worker, two clinical nurse specialists, three cancer information nurses, a general practitioner, a community nurse, a stoma nurse, a radiation therapist and a key support worker. These people were purposively selected because they were recognised as leaders in delivery of holistic support for people affected by cancer. They ranged in age from 30-65 years (average age = 53) with two males participating. There was one Māori key informant and one European participant. The majority (n=10) identified themselves as NZ European.

Focus group results

The results from the focus groups are synthesised and presented in this section. Focus group participants were asked to share impacts of cancer treatment on their life and how they managed during that time with the group. Cancer survivors pointed out gaps where their expectations for care did not meet their experiences of care. Impacts and gaps discussed by survivors were categorised as social, physical, emotional, and spiritual following the Te Whare Tapa Wha model cornerstones (Durie 1994). Impact management strategies were outlined using the adapted illness trajectory framework (Klimmek and Wenzel 2012) as the analytical frame. By using these two frames, what was already known about cancer impacts and the work of cancer survivorship served as the fore structure for analysing this new NZ data.

The focus group processes differed between the two groups. The Maori-specific focus group began with karakia and whakawhānaungatanga prior to any handing out of information sheets and consent forms. Use of these culturally indicated processes provided the opportunity for participants to make connections, researchers to show respect and to create a safe space for open conversations. All focus group participants were provided with food and koha to care for and respect participation in discussions of challenging topics.

Physical impacts

The Te Whare Tapa Wha framework identifies tinana as one of the four cornerstones of Durie's 1994 Māori health model. Tinana is defined in the te reo glossary as referring to the body (Moorfield 2005). Tinana reflects physical manifestations of health and wellbeing on the body.

Cancer-related physical impacts were described by all participants. Many described their struggle to manage specific physical issues. The issues mentioned included fatigue, weight change, bowel incontinence and comorbidity. The extent of physical impact and self-management ability varied among participants.

Focus group participants expressed varying levels of difficulty dealing with toxicities and side-effects during and after treatment. Although changes in bowel habits were usually readily addressed by the cancer care team, many other common side effects were described as predominantly self-managed.

Fatigue was a common physical impact mentioned by participants. One participant described how it felt prior to his emergency admission to hospital.

I found that I just didn't have any energy to do anything. I totally lost interest in everything. All I was really looking forward to was coming into hospital each day for radiation and having a little meal in the cafeteria and then it was time to go home and just be a total vegetable. I was actually in a very, very bad way, but I did not realise it until later...the thing was I didn't know I needed [support].

This participant's experience of fatigue led to a perceived loss of confidence in self-management ability and control. When he described this experience, his emotional reaction was so strong that he cried.

Some participants discussed the stress of learning to self-manage specific physical impacts encountered. A member of the multicultural focus group described uncontrollable weight gain contributing to a loss of self.

I didn't expect to get fat. It really freaked me out because I didn't know if I'd be able to lose it again. And the other thing was that [it impacted on my willingness] to do anything by myself...I hadn't been myself [in look or feel] for quite some time... It was quite freaky.

This participant described how she had to find ways to address an impact of cancer treatment that challenged her sense of physical identity.

Dealing with changes in sensation, including neuropathy and skin breakdown, was described by two focus group participants. As one person said:

The blisters on my hands were horrific. Each fingertip. The feet. I drove home and suddenly this pain was terrific. I went straight through the lights on the motorway because of the pain.

In a similar vein, another participant said:

I had no skin. It was raw and I was thinking what do I do here? They said it would happen. It is one of the side effects. It took me ages to find a cream that would soothe it.

These participants clearly describe the need for self-management of specific side-effects.

Comorbidity was raised in the Māori focus group session. One participant, speaking about her mother, identified that her mother's other health issues complicated communication and care.

She had all these other issues [lupus, arthritis], and trying to get them [doctors] to all talk to each other was impossible, and so then it was left to the whānau [to talk to the doctors].

Comorbidity management was described as a challenge for both cancer survivors and health professionals.

Emotional impacts

The Te Whare Tapa Wha framework identifies hinengaro as another cornerstone of Durie's 1994 Māori health model. Hinengaro is defined in the te reo glossary as referring to the mind (Moorfield 2005). Hinengaro reflects emotional manifestations of health and wellbeing.

Emotional impacts of cancer emerged incrementally in the focus group discussions as people shared their stories and felt more comfortable in the group. Some focus group participants became outwardly emotional as the group discussions progressed. However, the magnitude of the emotional impacts described and displayed varied between participants. More negative than positive emotions were described. These included shame, worry, uncertainty, loss, anger, fear, anxiety, sadness, and loneliness.

While the responses in this section are discussed mainly as single emotions to aid understanding; in reality, participants described a mixture of complex emotions in their narratives. For example, emotive words were used by Māori focus group participants to describe reactions to diagnosis and treatment. Words used included "a blow", "really hard going", "hit with two barrels", "stunned", "horrific" and "frustrating".

Worry was one emotion that linked many participant narratives. Cancer-related worries around 'will treatment work?' and 'what else will go wrong?' were articulated by some focus group participants. These worries triggered memories of fears for other participants.

One participant used the analogy of the Christchurch earthquake to describe the fear that she felt about not being able to manage emergency physical tasks due to fatigue. Her analogy reflected fear, uncertainty, worry and anxiety regarding the environment as being generally 'out of control', a feeling that seemed to resonate for most participants.

Focus group participants shared the universal experience of having a potentially fatal illness and the loss of what was considered 'normal' life into survivorship. Hair loss was described as a visual representation associated with cancer treatment loss.

With our women, there is always this thing about our hair, the fact that we are going to lose it. You can still keep your dignity. You do not get that from hospitals. You get that [elsewhere].

This participant described cancer-related loss, visibly portrayed as hair loss, being associated with the invisible loss of dignity for Samoan women like her.

For another participant, a painful loss was felt when she was told her cancer had recurred.

...that is the hardest thing, being told that you have got cancer AGAIN and having to tell my family AGAIN. That loss hurts.

Various permutations of loss were indicated by the data. Further, a sense of loss was palpable during the focus group sessions.

Fear was another emotion shared by some focus group members. One participant reported feeling fearful when her cancer treatment expectations for supportive care went unmet.

[I did not get] the support from the doctors and the nurses...my very first time. I was scared, you know, I was really scared...and I was a bitch...and I say that out here because I was, because of the way they treated me.

In this quote, anger was described as arising from fear. That anger related to loss of security and shattered confidence in oneself. At times, that anger was directed at health and supportive care workers. Feelings of anger arose from not getting the support expected during treatment and those feelings were described as persisting post-treatment. Two other participants described being frustrated by care expectations which were not being met by their respective cancer teams. Two cancer survivor participants described frustrations with experiences that did not match their expectations.

There was no debrief at the end of it. It was just you have finished; get out in to the big world. Hope it has worked. It would have been good to have had a bit of a debrief...

I believe I should have had tests, because bowel cancer can go to the bones. To this day I will not know and I have to let it go...[did they do everything they could because my cancer has returned in the bone].

The mismatch between expectation and experience for some participants was described as disruptive to putting the cancer experience into perspective and moving forward.

Another cause for frustration for some was lack of communication about process. Participants expressed confusion and frustration around knowing when their respective roles as patient or healthcare practitioner were finished.

Overall the cancer journey impacted on the feeling of being in control. Participants described how aspects of life and health were felt to be out of control.

Cancer takes away from you, it takes a lot of your choices away from you... there was that desire to maintain some sort of control over what was happening since health was out of control and body was out of control, and so, you just feel like controlling...something.

Control, or feeling in control, was identified as an antidote for the difficult feelings that arose intermittently for survivors.

In summary, a variety of emotions were described by participants across focus groups. These included loss and grief, fear, anger and frustration. Some of the negative emotion was directed toward health and supportive care workers due to perceived unmet care expectations. Most participants described how they still struggled to manage their strong, yet intermittent, emotional reactions to various aspects of the cancer experience.

Spiritual impacts

The Te Whare Tapa Wha framework identifies wairua as another cornerstone of Durie's 1994 Māori health model. Wairua is defined in the te reo glossary as spirit or soul (Moorfield 2005). Wairua reflects spiritual manifestations of health and wellbeing.

Spiritual and existential impacts of cancer were described by only a few participants. The spirit emerged as a contribution to strength in adversity for a few participants and it was expressed by one participant in the following way.

[What] strengthens us? [Most elements went under] Taha wairua, then it went out somewhere else, but it ended in that taha wairua box, and we need to understand and get clinicians to understand, for Māori whānau and for anyone else [most things are about spirit], because if you get it right for us, you will get it right for everyone else.

One participant described the importance of their faith.

Today I had my monthly calcium drip in the cancer day ward. Afterwards I went to the chapel, which is something I always do whenever I am in the hospital...

Another participant described continual efforts to try to find meaning in the experience.

He used to say to me that you're fine, there is nothing wrong with you, just go along, you are fine and it's still hard for him to understand that it is with you for life. You can't just shake it off. I'm still trying to understand what it means...

Whilst issues related to the spiritual were not often spoken about, a minority of participants from the multicultural focus group described the experience of 'spiritual crisis'. In contrast, acknowledgement and consideration of 'wairua' emerged from the Māori focus group data.

Social impacts

The Te Whare Tapa Wha framework identifies whānau as an important cornerstone of Durie's 1994 Māori health model. Whānau is defined as referring to extended family (Moorfield 2005). This is an important concept. This Māori term refers to both descent-based whānau and whānau who come together for a common purpose. Metge (1995) defines the two kinds of whānau as whakapapa-based whānau and kaupapa-based whānau. This acknowledges that for people, their whānau can be both their family of descent as well as those people they define as important in their support network (Central Cancer Network 2016).

The social impacts of cancer survivorship coalesced around managing relationships. When asked about treatment, most focus group participants discussed relationships with their cancer team. Relationships with health and supportive care workers were described as a key contributor to the experience of care.

Communication, as the basis for relationships, was described by the survivor participants in various ways, from effective to difficult. Some participants focused on connections they felt they had with their health professionals. One participant was proud of the collaborative relationship and communication he fostered with his oncologist.

They are not there just to fix me. I'm there to fix me as well. As soon as you convey that to them, they start getting more interested in you anyway, because, hey, this person is not just going to sit back and take what is coming. I have got a lot of strength out of that kind of interaction, even to the point of exchanging scientific papers with the oncologist.

While another participant described how the poor communication he experienced was fine, as long as he received what he regarded as a technically proficient service.

I just wanted to say the specialists that looked after me, they weren't wonderful. I sort of do not know that I would necessarily expect them to be. I wanted my surgeons to be really physically capable.

Conversely, a few participants described how they wished for more empathetic healthcare practitioner encounters. They wanted health and supportive care workers approach to convey 'love'/aroha or 'warmth'/empathy alongside clinical expertise, and were disappointed when this was not provided to them. A few participants mentioned that they did not feel heard.

I do not know how many times I had to jump up and down and say listen to me...

Similarly, one participant described feeling unsupported beyond the clinical focus of care.

The surgeons were not in any way connected to cancer really. They just took the cancer out. None of the nurses, none of the staff, knew anything about the support systems that I actually eventually kind of needed.

Different relationships and types of connections with health professionals were described. Participants held varying expectations for these interactions which impacted on their experience of care.

Two participants used the analogy of a bridge to show their desire for better connection. These participants reflected on the perceived gap between the clinicians' world and their own lived reality.

I became so aware of the gaps between patient and doctor and [nurses] and the need for there to be some bridge, call it bridge...(P1)

Massive bridge (P2).

These two participants described the need for a bridge that could link their personal reality with a clinical world that valued understanding of things like medical terminology and navigation of complex clinical pathways between departments. This was described as "...a

complex process in a foreign environment". The medical culture challenged people and this impact was described passionately by those in the Māori focus group.

As a patient, relationships with various clinicians were often established quickly without the usual application of cultural practices such as whakawhānaungatanga, which was perceived to contribute to communication problems.

if you cannot share it with your own family and if you cannot share it with your doctor, who can you share it with? You know, you are stuck there by yourself... some of the things they [clinicians] can offer [to make the journey easier], is whānaunatanga, whakapapa, whatever... to help walk you through.

Without the basis for connection and communication established with clinicians, some Māori participants felt they were not being treated with dignity and respect. Examples included one participant who described their first chemotherapy treatment as "let's stick you up, let's get you going, then we are out" while another described waiting 45 minutes to be unhooked at the end of her chemotherapy infusion. These participants wanted to find comfort, respect and a safe place to be in the foreign cancer environment in which they found themselves.

Treatment impacted on and challenged family relationships and roles. Most participants reported that they relied heavily on a main family member as a carer during treatment. One participant stated that she had wanted whānau to help her navigate.

It was about wanting somebody to 'love you' through it....wanting someone to walk [beside] you through it.

There were instances where a survivor referred to others being worse off, such as illustrated by one participant in the quote below:

As a [survivor] carer...I do not know how many times Mum used to say to me I am so lucky you are here. What about all those people who have no-one.

A main family carer was seen as integral to management of cancer in day-to-day life for some participants.

Conversely, some participants described withdrawing from whānau. One participant expressed relief that he moved away from his wife during treatment because he felt he needed to focus on himself rather than attend to her.

So, because my wife, who is still back home in Waitotara, she loves to be a doctor, so I have rushed through on the side. I said because this one is so serious for me, I want to do this myself. I will tell you what is going on. When I need you, I will call for you.

Some participants described perceiving a negative impact on whānau. Talking about this issue, one participant said:

My kids and my husband and my family...they have to go through these ups and downs that I have and the bad days and the good days that I go through. I feel sorry for them...[they didn't ask for this]... it has happened to our family...and it takes a toll on families.

This participant felt it added a burden to the whānau.

I had numerous short trips to hospital and I had a young family. I felt guilty the kids kept getting hauled out of bed in the middle of the night to go to their grandparents. They were quite uncertain. That was a huge thing. I also got quite weak and couldn't do much around the house.

These quotes relate to participants' attending to loved ones' feelings, actions and thoughts during cancer treatment but feeling powerless to self-manage the negative impact on the family.

One participant from the multicultural focus group described financial difficulties affecting social roles. She described both work and financial concerns.

I had financial concerns. I was the main breadwinner for our family and the worry was that if this does not work. I mean we were all right then, but if it did not work and [I couldn't work] ... we would then be falling into quite serious debt.

The overarching themes that arose from the focus group discussions around impact and impact management were that cancer impacted on life in various ways that required adjustment and self-management. The impacts that were described as most difficult to manage differed amongst survivors. Various physical, emotional, spiritual and social impacts were described. All participants reported experiencing physical impacts. Most described emotional and social impacts. Few described spiritual impacts. Participants developed strategies that worked, at times, for managing impacts. At other times, participants reported struggling to manage impacts effectively.

Cancer survivorship work

In this section, focus group participants describe how they managed life and health complexity using coping mechanisms and strategies. This addresses the second research question: What other factors contributed to life and health complexity, and coping for NZ cancer survivors?

Focus group participants were asked to describe ways they coped with the physical and non-physical impacts associated with cancer treatment. The mechanisms and strategies described are presented using the Klimmek & Wenzel (2011) cancer survivorship framework. This framework categorises mechanisms and strategies as illness-related, biographical and everyday life work. The focus group data in this sub-section is presented for illness-related and everyday life work. A separate sub-section for biographical work is missing herein because there was not enough data to warrant inclusion. Reference to biographical work may be inferred from rare comments pertaining to impacts, such as 'loss of self'.

Illness-related work

Mechanisms and strategies for coping with physical impacts of cancer and its treatment were described. The strategies described by focus group participants in relation to illness-related work included avoidant coping (e.g. denial, laughter), seeking support from family members, trying a variety of over-the-counter and complementary products for side-effect relief, and talking with others (e.g. such as staff of the Cancer Society or Māori navigator).

Denial was mentioned as a coping strategy. One participant stated "just the thought of having cancer, it's like a process of denial". Another person described asking for support as 'whakama' (meaning embarrassing or related to loss of mana), resulting in denial. This helped avoid the uncomfortable difficulty and embarrassment of taking actions to manage cancer-related impacts.

One focus group participant said "It is kind of a switch to actually ask for help when you have been doing just fine living your life, and suddenly things change..." The main strategy described was 'just getting on with it' amidst challenges presented by cancer, cancer treatment and life in general.

I found out that you have to believe in yourself even though things might be bad, just believe. I mean, that's what has got me through and today I work... and I am not supposed to be doing that...I just got on with life...You have got to have something to believe in.

Intermittent bowel incontinence was an illness-related concern raised that crossed over with everyday life work. Colorectal cancer survivors described how they readily received assistance with bowel continence from the cancer team during treatment. However, participants described sustained changes in bowel habits and ongoing management

challenges post-treatment. It led one person to pursue a practical strategy of "...a kit in the car [with] all the emergency things you [may] need for diarrhoea or nausea, like a water bottle, plastic bags..." Participants described a lack of awareness of post-treatment support options to address these types of issues which affected their ability to work, travel or participate in social activities.

A few participants found accessing information to be helpful. People described accessing information and support through health professionals, Cancer Society, friends, whānau or internet options. Helpful support options mentioned included joining a support group, finding cancer buddies through online forums, or by participating in a yoga class or other exercise program. Information helped some people find ways to meet their support needs and feel more in control.

Some focus group participants touched on ways they managed the less readily seen social and emotional challenges associated with treatment. The importance of social strategies was raised by a few participants. Some people mentioned whānau or a 'buddy system' as an important source of support. As one person said:

One thing that comes up quite a bit is the support of whānau through the process and also having to communicate with whānau about what is going in your lives as well. Sometimes I find that friends are better than whānau.... because whānau can get a bit too emotional, whereas friends you know...there is more of a chance to talk with them.

This quote relates to the importance of being able to talk with people who were not as emotionally involved as close family. It indicates the value of different sources of social support to enable access to those that at different times feels safe and fit for purpose.

At times, the conversations touched on loss of future security and loss of possibilities and opportunities. Personal management strategies were offered by some participants as a reaction to the loss narratives shared by group members. Two people described how they reverted to their traditions or things they learned from older relatives. A Pacific participant described that people she knew often chose to use both traditional medicine alongside Western cancer treatments. This was mentioned by a Māori participant as well.

Some strategies were described as helpful for people but were perceived to get a negative reaction in the healthcare environment. A Māori focus group participant described the use of laughter as a coping style in her family.

...what we [Māori] do when we are in pain, we laugh...and so our way [was] trying to laugh through a session, because it was really hard... Mum used to say some funny things and she would joke away about cancer and it was a way of dealing with the pain...

This participant explained that this coping strategy was judged as negative in the healthcare environment due to it being interpreted as incongruous to the seriousness of the situation. In a sense, laughter might be considered a form of denial, but it is a useful mechanism for some.

Coping mechanisms and strategies are personal. Focus group discussions reinforced the individuality of coping mechanisms and strategies found useful during treatment.

Everyday life work

When you have cancer, you don't just worry about what will happen to your body, you worry about what will happen to your life (Macmillan Cancer Support 2014, 68).

Mechanisms and strategies for coping with everyday life during cancer treatment were described. These overlapped with the data presented in the previous section on illness-related work.

At treatment end, everyday life work was seen to be the dominant area of focus. Most participants described lingering illness-related impacts disrupting everyday life work and a return to normal life. Some participants discussed setting new life goals at this time. Examples shared included things such as avoiding recurrence, eating well, exercising or coping through the week. These hopes and desires were described more as personal aspirations, and did not seem to translate into specific action plans.

During treatment, people reportedly felt that they were managing mostly well, but after treatment ended there was a change. People described holding 'end of treatment' as the goal, but after treatment it felt like nothing was happening and it was scary "...because I am not going to the hospital anymore" (K8).

The one thing I wanted when I finished was someone to help me set up what sort of exercise I was going to do.

The transition from the hospital 'safety net' where patients were urged to call their treatment team if they had any concerns, to a perceived post-treatment void in support, was described as a 'let-down' by some participants. The transition shock contributed to

feelings of anxiety that were described using words like “uncertainty” or “powerlessness” by participants. One participant was unhappy about this gap in care and described it as follows:

If there is a problem you are told to go back to your primary care provider, your GP, but in a world where you lost your job and finances are an issue, you have to pay for that privilege.

The cost of traveling to appointments, time off work, unsubsidised primary care visits and the cost of medications were specific examples mentioned as having an impact on everyday life. There were no specific strategies mentioned for dealing with these impacts except ‘just getting on with it’.

Focus group data highlighted opportunities for supported self-management intervention. Various management strategies were described but gaps were evident. Everyday life work was particularly challenged because of cancer-related impacts on finances and employment.

Supported self-management intervention impressions

The Flinders Program, illustrated through a vignette, was described to participants as a standardised yet personalised intervention that could be delivered in the hospital or community setting. As a strengths-based intervention adapted to peoples’ values and priorities, it enabled coping strategy development and use. A vignette was read aloud to participants.

John is feeling more unwell and is finding his usual jobs difficult to maintain. He is the main breadwinner for his family. The key support worker is part of the cancer team and talks to John privately in 3 sessions, for just a short time, while he is waiting in the day ward for his appointments, about how he is going in fitting ‘cancer’ into everyday life at home. Supported self-management encourages individuals to discuss what is most important to them at the time with a view to dealing with every day or practical concerns. The key support worker reflects John’s concerns and discusses with him strategies and ideas. Self-management interventions intend to help people acquire and practise skills to carry out different medical regimens and lifestyle changes as well as support physical and psychosocial transitions. John and the key support worker collaboratively explore John’s values, strengths, strategies and goals in order to develop a plan that will work for him and his whānau. Practice in carrying out strategies is also encouraged. A written care plan is provided to John. It includes discussed strategies, goals and any referrals. It may be of use at the time and/or when treatment ends. In this way, John is supported to develop the confidence and skills to self-manage more through his remaining treatment and post-treatment. It helps him develop strategies to deal with long-term impacts, return to work and with managing relationships differently. It allows him to move forward with greater confidence.

Participants were asked to describe their impressions on the approach presented. There was a mix of positive responses and concerns raised regarding the acceptability of supported self-management intervention. While, many participants seemed to identify promise in the approach, others were dismissive.

The impressions of supported self-management described varied among participants. Survivors' initial reactions to the vignette ranged from immediate rejection "I do not want a life coach" and "I do not like the name" to cautious consideration, such as "It is very easy to wallow in self-pity. Someone has to tell you to get up and go" which was also reflected in the quote below.

I think whoever this person is going to be and how that relationship initiates as long as you are the driver, and if that person is purely a rebound board...but that journey you do not always know at the beginning. I think over your radiation chemo pathway it happens in steps.

Assessment for support needs was one positive benefit foreseen from the approach. This was confirmed in this quote from a focus group participant.

One of the cancer nurses came and said that there are these things available for financial help. I tell people about it. My previous cancer nurse assumed that I did not need that financial help. I think one of the things that specialists could do is not assume they know everything about the person's situation, but actually ask are you needing any help with doctors' bills? Because that is what I needed help with and would have qualified for, but did not get, because they assumed I was well enough off not to need it, but I do not think you can assume.

Along with identifying some positive potential for supported self-management, there were a variety of concerns or barriers described by focus group participants. The concerns raised about supported self-management intervention were largely around terminology and 'fit' with existing supports.

One participant in the Māori group interpreted supported self-management to mean support from others. Although most people in that focus group stated their preference for their Māori cancer navigator to be their support person, one person stated that support could be provided usefully to others by someone who was experienced, knowledgeable and caring.

Experience and the wairua [matters]...it does not matter where you are from.

In general, the concept of supported self-management was not seen to be easily grasped by focus group participants, and only a minority stated that it might be a useful addition to

their care. There was concern raised from members of the Māori focus group that this approach would replace existing staff, such as the Māori navigator whose job it was “...to support the whānau...to make their own decisions and to empower them. [It] is about whānau ora.” These concerns are addressed in the discussion.

The vignette-based focus group enquiry explored how The Flinders Program was interpreted from the perspectives of people affected by cancer. The responses to the vignette fell into three main categories: individual capacity, support from others, and self-management environment. These views expand the knowledge base on NZ survivors’ views on supported self-management program interventions and their enablers and barriers.

Individual capacity to participate in self-management was described as being affected by physical functioning, communication skills, self-confidence and desire for self-determination. Capacity varied depending on level of wellness experienced.

Support from others was reported to both hinder and enhance motivation for self-management at different times. It was generally acknowledged that the health system addressed most clinical issues but that this led to feelings of disempowerment after treatment. Self-confidence needed to be rebuilt if the same levels of support were not taken up by whānau. A health environment, including whānau, which is supportive of self-management, was described as contributing to improved overall wellbeing. If people affected by cancer are supported to be an integral part of the treatment process this can counteract some of the impacts of unintended medicalisation described by key informants in the next section.

Key informant interview results

The results from the key informant interviews are synthesised and presented in this section. Key informants were asked to share their views on cancer impacts and coping for those people affected by cancer with whom they worked. They were then asked their views on the acceptability of supported self-management approaches. The feasibility of carrying out a supported self-management intervention program in the hospital-setting, including foreseen enablers and barriers, was then discussed.

Views on cancer survivor impacts and coping

The concept of surrender and survivors becoming a bit “lost to oneself” which impacted on individual capacity to self-manage was touched on by at least two key informants (K5, K12).

We try to see people’s individual needs, and as people come through the day unit or the ward, they do present themselves with their personality, their hold on “this is who I am”, and we really try to support that, but actually the health system is not really structured for you to be too individual (K5).

Another key informant described this loss of self as being compounded by the hospital culture of fixing; where patients are encouraged to be passive in the hospital “...where things are done to you” (K6). Cancer survivors described their ability to self-manage in the focus group data but this may be discouraged in the hospital-setting.

The recognition of impacts on identity for patients was not brought up by survivor participants in the focus group sessions. However, it was also not specifically raised as a topic. Because biographical work is more personal, ephemeral and not readily discussed, it may be less likely to be disclosed by survivors.

During the interviews, one key informant said “my experience of people in a time of stress....is that people are not good at reaching out...” (K12). This may refer to a reluctance to initiate conversations about less concrete topics. Another key informant suggested that people sometimes “...sort of need permission to need [or seek] help” (K1). Patients were described by health and supportive care workers as not wanting support, at times. According to some key informants, people affected by cancer do not want to be seen, labelled or judged as “not coping” or that “something is wrong with them” and may feel it is “not OK to need help”.

Conversely, some patients readily ask for support. One key informant mentioned assisting with co-morbidities or other non-cancer related issues as an additional, but necessary, part of her role at times. She described working outside her scope of practise to meet patient need.

I have been working with this couple, they have an incredibly complicated [cancer] journey, now he has some cardiac issues. The wife rang me yesterday and said, look I do not know if you are the right person, but can you help. I said of course...and I was able to sort this situation out for them (K1).

Another key informant described confusion around discharge procedures which led to feeling stretched beyond capacity.

I discovered we had no idea when to discharge an oncology patient. We were hanging on to people long after we should have been and doing follow-up phone calls. Then we'd get overworked [and overwhelmed] and couldn't do our work we had in the day (K10).

Health and supportive care workers described feeling frustrated about not being able to do as much as they want to support patients. Key informants described the need for them to focus on patients' physical impacts, which sometimes precluded a holistic approach. One key informant wanted to avoid opening "a big, big can of worms that you can potentially open" (K6) with little opportunity to do justice to the issues. This key informant wanted to avoid holistic care and discussions of self-management in order to protect practice boundaries and focus on management of physical impacts.

All key informants acknowledged that cancer treatment had impacts on life during treatment. A few acknowledged post-treatment issues. One key informant used the example of bowel management to illustrate the often immense and lingering impact that colorectal cancer had on peoples' lives. She described issues with bowel management affecting relationships, as a constant personal reminder of the cancer experience, and as a trigger to thoughts of cancer recurrence and the uncertainty that goes along with that "monkey on your back". Whilst some key informants wanted to improve their culturally safe practice in an effort to establish effective relationships between health and supportive care workers, and patients to deliver holistic care, others indicated that they did not see this to be a part of their role.

Views on supported self-management acceptability

Key informants were presented with a synopsis of self-management support and were then asked to share their views on the approach. Specifically, they were asked about their experience with supportive care as well as their views on the barriers and enablers to a supported self-management study in the cancer clinical setting.

A gap in evidence for survivorship interventions was identified as a positive aspect of progressing a study of supported self-management. Establishing credibility and 'buy-in' for or against intervention was viewed as an important aspect of this type of study taking place in NZ.

[Do] people need this kind of support? Not everyone does, and people need it to certain different levels, but I think just having the [intervention] evidence would be really powerful...And for us, I guess it is helpful in knowing what works for people, and just planning programmes (K8).

Pilot interventions were indicated by key informants as an acceptable way to generate evidence, however, not without challenge to staff.

I think we are all doing our best, all trying to get it right...you might literally run into us [as a barrier], even more than the patients on some level because we are not accustomed to considering that there might be a process that we can actually work with...that [new process] might be challenging to us...because we have been working around the corners, doing everything else to try and get things done (K5).

The positive aspects identified for supported self-management intervention were the need for a standardised approach to holistic assessment, the need to address the gap in survivorship support and the need for more survivorship research. Potential benefits were more readily described by key informants than focus group participants.

Many key informants saw supported self-management as a way to promote routine assessment for support needs. One key informant commented “there is certainly a lot of support for [standardised assessment] at the moment” (K2) but not a lot of it happens consistently.

Some people get seen [by social workers] for whatever reason, they have more easily identified needs or they are more vocal about their needs, so they get referred into our service...and others have just as much need and do not get seen and do not even know social workers are there, so it is very inconsistent and random assistance (K8).

There was recognition from both focus group participants and key informants that it was difficult to know when people could benefit from support but it was important to assess needs and provide patients with the opportunity to discuss pre- and post-treatment strategies.

I would want to make sure that every single person has had the opportunity to sit down quietly and discuss what is happening, and ask questions, and also be delivered information orally, written, and [digitally]...I would like to think that every person would have a contact that they know they could get hold of and talk things through....and for them to know where they can connect back and have that information repeated or reinforced (K3).

Some key informants suggested that standardised assessment would enable them to do specific things to help people support patients to become self-managing or engage in problem-solving.

...here are some things you can do for yourself, or maybe with a bit of scaffolding we can [help] get you there... (K9).

...if people can de-escalate, then they can start problem-solving, they can start to think about stuff... (K11).

There was general agreement that assessment and intervention, if routinely applied, resulted in better support.

The potential for supported self-management intervention to ease treatment transitions was another point raised in favour of supported self-management intervention. Key informants generally expressed a desire for patients to be well supported at post-treatment transition time because they often become, effectively, institutionalised or semi-dependent on the healthcare team through 6-months or more of frequent procedures, hospitalisation or 'medicalisation'.

... there are kind of inevitable dependencies that we create with people, because we need to, we need to make sure they are safe, we need to make sure they feel safe, and we need to actually make sure that they are able to comply with certain things that make their treatment as safe as possible.. but, over the years, I have really grappled with myself over [creating] this dependency. I really do think I have come to the conclusion that it is necessary...but then what? Then what? This [program] seems to have a real value in terms of just being almost able to help people re-gather themselves up in a way... (K6)

The 'medicalisation' that inevitably occurred during treatment was seen to contribute to personal transition difficulties once treatment ended.

One key informant identified the chronic nature of cancer for survivors in saying "you have this intense acute phase, then every now and then, you might have an acute episode in the chronic post-treatment phase" (K4). The inevitable need for follow-up care highlighted by this key informant related to the importance of strong linkages to post-treatment 'aftercare' or follow-up care.

...patients disappear for a reasonable period of time so re-linking them up [to primary care] to make sure that everything else is kind of integrated into their care would be very useful (K7).

Most clinicians agreed that intervention that supported transition could be useful. This support, which needed to be initiated during treatment and prior to handover to primary care, could consist of sign-posting likely post-treatment side effects, provide alternative pathways to survivorship care and address normal post-treatment anxiety.

In summary, whilst a few focus group participants identified potential benefits of the intervention, key informants uniformly supported an evidence-based standardised assessment and intervention approach, linked with clinical flow, and incorporating discharge planning as well as survivorship care pathways. There was recognition of potential benefits of hospital-based supported self-management intervention.

Views on supported self-management intervention feasibility

The key feasibility concerns raised by key informants were related to intervention timing, setting, and delivery. Participants' views varied but the need for flexibility and adaptability in timing, role and delivery was emphasised. Important intervention elements pointed out as needed included ensuring confidentiality, provision of a range of options for information delivery, signposting to further information, and allowing for referral and follow-up in conjunction with other clinical strategies and plans.

Intervention timing

Important points were raised related to intervention timing. The first was variability in readiness to engage with self-management. One person strongly felt that the earlier the better for any cancer patient support intervention.

I think the sooner the better. You try and kick in further down, you are already defensive; you are already withdrawn, you are already a little bit mistrusting...so build up that relationship [early] (K4).

Two people agreed that any support intervention must be put into place "...as soon as possible, early intervention" (K4, K5). However, the opposite was also suggested in putting the focus on discharge time "when distress levels are usually lower" (K10). Additional brief comments were made on the importance of repeatability of assessment and contact so it is not a one-off, and the need for a process for referrals or sign-posting which can be followed up on. In summary, timing and follow-up were indicated as important components of intervention, but no clear consensus emerged on appropriate supported self-management intervention introduction or follow-up timings.

Intervention setting

No clear consensus on intervention location emerged either. The acceptability of the location of the intervention was discussed. With regard to hospital-based support, one Māori focus group participant voiced her preference for a community approach.

...because it is all about that whakawhānaungatanga, it is all about bringing [to the home] and she was then able to bring in the whānau and I think if you do things within the hospital setting, it can become a little bit sterile...

Another participant thought it was possible to offer support in the hospital if cultural safety could be enhanced.

I would go to the clinic if I know I was going to be in a safe area. That is what it is about for me...being in a safe environment [where] I can feel safe in there...

On the other hand, a key informant identified that hospital-based intervention was preferable for some people "...because it does legitimise more powerfully" and that "the hospital is the place where [people] do their illness, and so support would sit within that...because when I leave the hospital, that is where I leave it" (K12).

Overburdened clinic staff and lack of resources were seen as a setting barrier.

I can see that we [oncology nurses] only really have time for the totally medical focus unless a crisis sort of jumps at you (K3).

Already overburdened hospital-based roles contributed to the disconnect between what people who work in the health system can provide and what cancer survivors expect or want by way of support. Another key informant described being in "clinic zone" where there is not a lot of time to explore feelings or "drill down on where [the patients] head is in all of this" (K6). The potential value of non-governmental organisations (NGOs), such as the Cancer Society, in the community setting was raised by one key informant. However, for some people NGOs were described as not approachable or 'not the right fit'.

We were pointed towards Cancer Society, but...for me, it was about older, white women with pearls and twinsets, and you know, doing charities and stuff. Sorry. From a cultural perspective it is really hard to step into the Cancer Society and go, can I have some help please? I tried to approach the Cancer Society but it was too hard...

Concerns were raised about whether this intervention was the best way to improve the experience of care given limited resources. However, there was no alternative options suggested.

Intervention delivery

Initial reactions from both focus group participants and key informants upon presentation of the vignette related to 'who'...who would deliver the intervention acceptably.

The role and approach of the interventionist was seen as a key to intervention success. One focus group participant indicated that there needs to be a balance between being too sterile, and getting "all whānau". Another person stated "it needs to be a social worker to do it right" while the opposite view was also mentioned.

They would have to have a passion to do what they do. If someone has a social worker's certificate to do the job, that means jack. Experience and the wairua that is what matters...

This is someone who knows the journey, who has been through it. The qualities of someone who has been on the journey to do this role has to be considered. For our teenagers, Grandma was the best coach.

Key informants identified individual barriers to intervention delivery. Individual barriers included health professional perceptions of the support patients want or do not want.

There was no clear consensus on interventionist requirements. Among clinicians, the most commonly held view was that the interventionist needed to be someone with a qualification. It was proposed that this might foster their confidence in referring patients to the interventionist. This contrasted with the view of the focus group participants that the person-centred approach of the interventionist was key, no matter whether the person had a qualification or not.

Intervention outcome measures

The key informant interviewee participants were asked about outcome measures.

Psychosocial outcomes were mainly suggested. Key informants identified that evaluation of the intervention must include patient-reported outcomes including "how people feel they are coping", "whether people feel informed", "desire for involvement in decision-making", monitoring if people feel "treatment goals made a difference to outcome" (K6), as well as the impact of fear of recurrence and lingering anxiety or depression.

Clinical and process outcomes were also suggested. Clinical outcomes suggested included 'did not attend' rates, referral rates, complication rates, unintended hospital stays

and other health outcome measures. Process outcomes suggested included rates of GP visits during and post-treatment.

The choice of outcome measures for the phase two study were based on key informant suggestions, published protocol guidance, and information from the literature review. The key outcomes of interest were indicated to be measures of coping self-efficacy, self-management competence, resilience, distress, quality of life and patient experience. Some types of clinical and process indicators were also suggested for inclusion, but were less easily operationalised in practice.

Data summary

In phase one, people affected by cancer treatment were asked to draw on their lived experience of cancer to identify impacts of treatment and management strategies. The analysis of qualitative data collected followed Thematic Analysis and Framework Analysis with use of a comparative method of developing themes (Baszanger 2012). The analysis explored survivors' experiences of cancer as a chronic condition included identification of codes and the grouping of codes into themes. The results from phase one were utilised mainly to determine whether to progress to a phase two study.

Focus group participants described physical, emotional, spiritual and social impacts of cancer that they managed in various ways. The differences in participants described experiences reflect individualised treatment impacts and management which lend themselves to personalised intervention.

Key informants shared their views on impacts and coping by patients. There was agreement that substantial impacts were felt but there was no clear consensus on where the responsibility for impact management and coping strategy development best fit.

The second purpose of the phase one study was to ascertain survivor and health and supportive care worker views on a vignette that described The Flinders Program. Key informants seemed to better understand the intervention at the outset, compared to focus group participants. Phase one participants across the focus groups and key informant groups engaged with the vignette and lots of questions were raised. Questions were asked around appropriate timing of the intervention, who could deliver the intervention, and outcomes to be assessed.

There was considerable reluctance voiced around the appropriateness of a 'one size fits all' approach, as implied by the example vignette. This likely related more to the difficulty the author experienced in succinctly explaining the intervention, rather than a critique of the intervention itself.

Participants' views of what a supported self-management intervention entailed (i.e. who, where and when) differed; however, the data clearly indicated a desire by participants for better support for the real-world impacts of cancer, particularly during post-treatment transition.

No focus group participant or key informant voiced any major objections to conducting a pilot study. However, it must be noted that participants might not have wanted to share any negative thoughts about the intervention to avoid perceived disrespect to the author. Given the data, it is hard to identify how prevalent this sentiment might be. Therefore, the phase two pilot study was initiated to generate more evidence about the acceptability and feasibility of administering a supported self-management intervention program.

Intervention adaptations suggested were incorporated. The Flinders Program was developed in Australia and key adaptations were deemed to be required for NZ settings. The adaptations suggested were inclusion of whakawhānaungatanga, procedures to invite participation by whānau, and koha as a recognition of the gift of time toward the research. These adaptations were mainly aimed at addressing 1) cultural and social factors and processes, and 2) environmental barriers.

Discussion

NZ patient and survivor experiences and views on the acceptability of supported self-management intervention were explored with a purposively selected group of cancer survivors and healthcare practitioner key informants. The resulting data indicated that there are extensive life impacts of cancer, some unmet expectations for care, and many self-management strategies being employed. In this section, specific concepts from the data will be discussed and compared with the literature (noted in Chapter three). The strengths and weaknesses of the phase one methods and results will also be outlined.

Cancer impacts

Cancer impacts on life and challenges self-management. Cancer is described as an interruption to normal life. Its impacts can be substantial and varied. The impacts described in the phase one study aligned with the Te Whare Tapa Wha Māori health framework: body (tinana), mind (hinengaro), spirit (wairua), and friends/family (whānau) (Durie 1994).

Participants' descriptions of the life impacts of cancer were consistent with both the NZ literature (Doolan-Noble et al. 2006; Egan et al. 2014; Hutt Valley DHB et al. 2006; Koea 2008; O'Brien et al. 2010; Rumball-Smith 2009; Slater et al. 2013; Walker et al. 2008) and overseas literature (Baravelli et al. 2009; Ohlsson-Nevo et al. 2012; Richardson et al. 2011; Watson et al. 2007). The literature suggests that the life impacts of cancer are multidimensional and lingering. Although individual cancers may take a varied clinical course, people affected by cancer live with the universal experience of having a potentially fatal illness, and often surviving with, through or beyond cancer for many years. Living with, through or beyond cancer involves managing intermittent yet lingering cancer-related impacts on emotional, physical, social and spiritual health.

Significant impacts across domains were named. Impacts of cancer on individuals and whānau have been well documented in the literature. The study data indicated that most focus group participants expected health professionals to consider the holistic impacts of cancer with the goal of achieving wellbeing.

Physical impacts described during treatment were similar to those identified by other NZ cancer survivors in the literature (Egan et al. 2014). Additional impacts specific to colorectal survivors participating in this research were neuropathy-related sensation changes, weight fluctuations, bowel or ostomy issues, and comorbidity challenges.

Emotional impacts described during treatment included distress, worry and anxiety. One study found that up to 58% of cancer patients experience some form of anxiety and depression (Massie 2004). This corresponds to the wider literature (Hewitt, Greenfield, and Stoval 2006; National Comprehensive Cancer Network 1999; National Cancer Survivorship Initiative 2013) that describes the emotional rollercoaster through the cancer journey. Emotional impacts named in this phase one study were grief and loss, fear, anger and frustration. Two international studies with colorectal cancer survivors found that uncertainty

and stress is associated with low mental health satisfaction (Pan and Tsai 2012; Galloway and Graydon 1996).

Spiritual impacts described in this study correspond to the limited NZ and overseas literature (Egan 2009; Puchalski 2012). However, this was an area touched on mainly by the Māori focus group participants who readily referred to wairua and disruptions to wairua in conversations.

Social impacts, particularly the importance of the healthcare practitioner relationships, are described in this study. Research from Australia points to the importance of these relationships to Australian survivors and the significant loss associated with disruptions to these relationships, particularly at treatment completion (Jefford et al. 2008).

There were individual and group differences in how much emphasis was placed in each cornerstone of the Te Whare Tapa Wha framework (Durie 1994) in narratives. In general, Māori participants described greater challenges around the social, emotional and spiritual impacts of cancer while non-Māori participants spoke more about physical impacts and challenges to everyday life. This is consistent with literature on Māori experiences of cancer (Slater et al. 2013; Walker et al. 2008). In literature around Māori experiences of living with and beyond cancer there is a weaving together of talk about physical diagnoses with reference to disruptions in the spirit, emotions, or mind (Britt et al. 2014; Slater et al. 2013; Walker et al. 2008).

The phase one study data highlights both similarities and differences in emphasis between cancer survivors and health and supportive care worker key informant narratives. For example, one difference noted is that key informants did not emphasise relationship and communication issues as much as cancer survivors. This may be related to differing perspectives. During the phase one sessions, cancer survivors seemed to speak from the individual and whānau perspectives while key informants vacillated between the individual and system perspectives.

Differences in emphasis can relate to profession or lens. Key informants tended to initially discuss physical impacts that impacted in other quarters of Durie's (1994) framework. Studies published in medical journals emphasise substantial lingering physical impacts of colorectal cancer treatment (Pan and Tsai 2012; Dunn et al. 2013). In contrast, studies published in social science journals and books emphasise the significant impacts of cancer survivorship on cancer survivor identity, emotions, sense of wholeness and purpose, and

relationships (Muzzin et al, 1994; Kelly & Millward, 2004; Winch, 2013). However, there were more similarities than differences overall between focus group participants and key informant views on the holistic impacts of cancer and its various treatments.

Participants in the phase one study described cancer-related impacts on people affected by cancer. These impacts were described by focus group participants as intermittent and lingering. Key informant participants acknowledged impacts but were focused on addressing physical issues.

Cancer survivorship ‘work’

The work associated with cancer survivorship was a universally shared experience across focus group participants. Klimmek & Wenzel (2012) refer to the use of health management strategies as the ‘invisible work’ of cancer survivorship. Personal coping and self-management strategies for managing this work were described by participants, with the post treatment transition seen as a particularly complex and difficult period where expectations for care and self-management were challenged. Personal and system barriers to being able to address support needs were identified.

Overall, regarding illness-related work, survivor participants described taking personal responsibility for doing what they needed to do to meet their needs. When asked about what could have been helpful, participant responses focused on social support delivered one-on-one by whānau or health and supportive care workers. Research into NZ cancer survivor experiences has indicated that people affected by cancer would like more timely information, better support, and help fitting the cancer journey into the context of everyday life (O’Brien et al. 2010).

Support to help survivors set specific, motivating goals is something that could be provided by health and supportive care workers or peers via supported self-management programs or other approaches (Doran 1981). Research indicates that cancer survivors are motivated by healthcare practitioner recommendations regarding wellbeing support and behaviour change relating to exercise and diet (Michie et al. 2008; National Institute for Health and Clinical Excellence 2007; Ryan, Patrick, and Deci 2008).

Most key informants indicated that they would like to do more to support cancer survivors in an evidence-based and timely way. The two key informant nurses who did not see value

in supported self-management felt that their role needed to focus on clinical care delivery. There was a will to provide holistic support shared by most healthcare practitioner key informants, but system barriers were described as prominent. This included lack of time and the need to focus on prioritisation of clinical needs. Whilst system barriers do pose issues for delivery of supported self-management intervention programs in the hospital-setting, there is potential for beneficial offset. A supported self-management intervention program can offer an approach to substitute necessary dependencies with strategies for self-management.

Communication is a key area of everyday-life repeatedly raised. There was a tension that emerged between the views of participants that preferred to talk things through with someone versus those that preferred to keep things to oneself. Both have evidence from the literature. Support is often expressed by offering survivors the opportunity to talk it through. This is thought to increase a sense of alliance, insight, and opportunity to express thoughts and emotions (Wampold 2001). It is not for everyone. Some people prefer to keep silent. A code of silence has been identified as a component of coping by survivors (Zhang and Siminoff 2003). This tension in views on the importance of communication reflects different coping styles and signals the need to allow for multiple tailored approaches to providing survivorship support.

Despite different communication preferences, the addition of a specific rapport building component into intervention delivery was indicated by the data. This is consistent with the literature which identifies the importance of the relationship and alliance in the therapeutic process (Wampold 2001). This may be done through processes to support whakawhānaungatanga and to allow for whānau inclusion, including whakapapa, as culturally safe practice (Pitama, Robertson, and Cram 2007; Slater et al. 2013).

Biographical work was not prevalent in the data. Because biographical work is more personal and ephemeral it may be less likely to be directly disclosed by cancer survivors. However, reference to 'loss of self' in focus group participant narratives alludes to Bury's (1994) chronic-condition related concept of biographical disruption.

Most focus group participants agreed that better support interventions for people living with cancer in NZ would be useful. The challenge is that cancer survivors experience a wide variety of life impacts, hold differing expectations for care, cope in various ways, and want access to support from different people at variable times and locations. Can one intervention address all these challenges and improve the experience of care? The

purpose of the phase one study was to inform a recommendation on whether to proceed with a phase two feasibility study of a supported self-management intervention program to see if this was possible.

Supported self-management intervention views

The phase one study ultimately centred around views on whether The Flinders Program can improve the experience of care. While reactions to the intervention vignette or synopsis were equivocal, several concerns were raised. It is helpful to note that supported self-management intervention was a new concept introduced for the first time to many key stakeholders. It is not clear how much participants' understandings of the approach through the vignette matched the reality of The Flinders Program. This alludes to the complexity of terminology and definitions in this field. A more understandable lexicon is required considering the misunderstandings of terms that likely occurred among participants. This terminology confusion introduces potential bias and is a known limitation for research in this field (PoCoG 2012; Jefford et al. 2015) and with The Flinders Program (Lawn and Battersby 2009).

The impact and coping data indicated that cancer survivors found ways to self-manage, but more support was desired to fill gaps in care. A recent NZ study found that personal attitude and appropriate social support, alongside clinical support, were considered key contributors to getting through treatment (Egan et al. 2014).

The focus group data indicated that ongoing adjustment is required to adapt to being a cancer survivor, manage treatment, achieve wellbeing through cancer and cope with lingering impacts. These were key themes that aligned with overseas studies of colorectal cancer survivorship reported in the literature review. Accordingly, supported self-management interventions were identified as an approach to help people "...accept their disease, and then learn how to live with cancer and its various ramifications..." (Chao et al 2010, 2279) as well as to enhance perceived self-control over managing lingering side-effects (Kidd et al 2008).

There was concern raised by Māori focus group participants about whether the intervention would take the place of existing supports, specifically the Māori navigator. It was explained that the interventionist would ideally be working alongside the Māori navigator, during treatment, to provide links or bridges to culturally and spiritually safe and

acceptable options for treatment support if, and when, needed. This is important because research shows that support carried out poorly or with insufficient cultural awareness can be detrimental to the cancer survivor and negatively influence willingness to access future support options (Dew et al 2015).

The capability of the interventionist was seen as critical to intervention success. A necessary balance was inferred by participants. This balance was based in collaboration. It was manifested as the program facilitator encouraging self-management, yet still encouraging survivors to access support provided by whānau, health and supportive care workers, and other non-health specific support workers. Multiple support options were preferable to less.

Regarding intervention timing, setting and delivery, no clear consensus emerged on these components. The data did indicate that the intervention needed to address the important emotional, physical, social and spiritual aspects of the cancer journey for the individual and whānau. An intervention that addressed these domains might be able to be delivered during treatment to address survivorship. Therefore, flexibility and personalisation of intervention delivery was important. The interventionist would need to tailor the intervention to reach concordance between the various priorities, needs and goals of individuals and whānau affected by cancer. Finally, supported self-management intervention in hospital clinic settings may help address cancer care gaps identified in NZ, but adaptations to the approach and the need for more research was clearly indicated.

Strengths and limitations

Qualitative research is subjective by nature. Narratives are affected by memory, perception, social bias and context (Denzin and Lincoln 2005). The phase one study generated insights into impacts of cancer, coping strategies and the potential of The Flinders Program as an acceptable survivorship support option in the hospital-based cancer care setting. Focus groups and key informant interviews were chosen as the methods of qualitative enquiry in this study (Patton 2002; Strauss and Corbin 2008). The aim was to inform whether to proceed to a phase two feasibility study.

Focus groups are an inexpensive method that can aid respondents' recall of the cancer experiences shared by members of the group (Denzin and Lincoln 2005). During the focus group sessions, there was a lot of material to cover in a short period of time. In following

best practice, the focus groups were limited to 1.5 hours (Silverman 2005). However, there was a larger number of participants than usual in the multicultural focus group. This time constraint impacted on the depth of data gathered and questions asked in both groups. It hindered understanding and discussion of The Flinders Program. There were differences, and possible misconceptions, noted in how people interpreted the vignette and the nature of the intervention. However, the vignette did not seem to aid group participants' understanding of the intervention and it impacted on perceptions reported by participants and the subsequent data analysis. In hindsight, it may have been more useful to conduct interviews with both survivors and health professionals to clarify the intervention presented. Other options for presenting the intervention include demonstrating the process live with a participant while others observed, or showing a video of a care planning process.

Key informant interviews were also subject to limitations. Key informants, as experts in their field, were being asked to share their views on something they may not have had much knowledge about (i.e. The Flinders Program). Therefore, their view relied on assumptions. Health professionals' perceptions of what constitutes the practice of person-centred care and those of people utilising the healthcare system can be quite different (The Health Foundation 2014).

Limitations are inherent in any study design. One key limitation in this study across both methods utilised was self-selection. Participants chose to participate. It is not known how these participants' views differ from the views of non-participant survivors. Other limitations include not knowing the extent social desirability and acquiescence played in respondent responses to make the researchers feel good or establish fit within the group (Patton 2002; Strauss and Corbin 2008; Liamputtong 2011). However, the nature of the conversations was felt to be honest and emotional. Participants' comments were frank and there were indications of considerable agreement in the data around key points. Many of these points aligned with literature.

This study had significant strengths. Focus group participants stated that they 'found benefit' in sharing their experiences (Winch 2013; Liamputtong 2011). Participants shared their experiences with others who have had a similar experience which may have shifted how they thought about their experiences. Interviews were conducted with health professionals and affirmed their expertise in the field. Reflexivity was practiced providing research integrity. A journal was used to document any observed personal reactions and

potential influences on choices made about the research. This journal and other observations were discussed with the research supervisors or study advisors.

Another strength of this work was that a Māori only focus group was held, in addition to a separate multi-cultural focus group. This aimed to provide a culturally safe context guided by Māori perspectives.

Analysis in qualitative work needs rigour and transparency. This can always be improved. For example, qualitative studies of this nature may use an independent coding process to improve rigour. Consideration was given to the need for the use of an independent coding process and further in-depth analysis of the phase one data. Based on the study objectives, it was determined that breadth be prioritised over in-depth qualitative analyses. So, comparisons based on ethnicity and gender-specific narratives were not pursued, for example. The data were not analysed at this level because the objectives of this phase one study were to determine the perceived 'fit' and acceptability of the intervention in NZ and inform a recommendation to pursue a phase two exploratory study.

The focus groups and key informant interviews as methods were considered the best way at the time to gather information that provided a valuable perspective on peoples' experience of impacts, perceived gaps in care and views on the acceptability of intervention that may address those gaps. Further limitations and strengths relevant to both studies are discussed in Chapter six.

Implications

There is a growing body of NZ-based research that describes cancer survivors experiences and gaps in expectations of care (Egan et al. 2014; O'Brien et al. 2010). However, there is a lack of published 'intervention-science' based research in NZ. This study aimed to contribute to the limited international survivorship and intervention literature with a NZ perspective. It was guided by indigenous perspectives on survivorship and potential interventions to improve the experience of care for Māori and non-Māori survivors.

This research provided an opportunity for people affected by cancer and clinicians to contribute to quality improvement. Focus group participants clearly identified support gaps and unmet expectations for care. Key informants identified the need for more survivorship

research in the NZ context and, for most, the desire to provide better support to address inevitable dependencies created during cancer treatment in the hospital care setting. Most key informants described wanting to provide better support. There were no obvious solutions suggested by focus group participants or key informants on how this could be done.

In this thesis, the premise proposed was that the experience of cancer survivorship may be improved by delivery of a supported self-management intervention program alongside clinical care in the hospital setting. The literature review indicated potential utility of the approach with emphasis on the barriers to and potential benefits of the approach. Supported self-management interventions were identified as potentially beneficial for some people at some points in time. Focus groups and key informant interview data indicated mixed reactions to The Flinders Program vignette. However, there was agreement that enhancing and supporting individual and whānau capacity to self-manage during treatment may be helpful.

The recommendation to pursue a phase two study was based on a review of the literature combined with analysis of data gathered from focus groups and key informant interviews. The summarised data indicated a gap in survivorship support existed and The Flinders Program offered a potential pathway that may be acceptable in light of equity considerations and hospital-based delivery. There was no compelling reason provided by phase one participants to not proceed with a phase two pilot study.

CHAPTER 5: Phase two feasibility study

This chapter describes the methods and results for a phase two supported self-management intervention program feasibility study. The specific objectives were to:

- Test study design aspects of recruitment, randomisation, intervention delivery and assessment by linking in with clinical flow in ambulatory care clinics;
- Provide insights into intervention content as well as identify enablers and barriers of key aspects of intervention delivery;
- Explore and compare outcome measures of self-efficacy; and, measures of global quality of life, distress, resilience and patient experience.

The overarching aim of this study was to explore the acceptability and feasibility of supported self-management intervention delivered in the hospital-based cancer care clinical setting. After theoretical knowledge gained from the literature review and qualitative phase one work established the study foundation in the earlier chapters of this thesis, pilot work reported in this chapter informs the acceptability and feasibility of conducting this type of survivorship intervention in NZ hospitals.

NZ-specific supported self-management interventions designed to support cancer survivorship do not currently exist. The literature review indicated that supported self-management programs are a fruitful area for further study to address this gap (Sarfati, Koczwara, and Jackson 2016; Minister of Health 2016b).

After development and review of program criteria, the decision was made to pilot The Flinders Program out of Australia, instead of developing and testing a new intervention without established evidence. The Flinders Program has been widely utilised and evaluated favourably in Australia (Battersby et al. 2007; Battersby et al. 2010) and this published literature provided a rich source of data for reviewing the program in light of the criteria. Of the three programs reviewed, The Flinders Program most closely met the criteria described in Chapter three. The first criterion was that the program needed to be well-structured to ensure fidelity and The Flinders Program was able to be structured into sessions, yet tailored, to meet this requirement. The second criterion was that the program enable tailoring for use across health conditions and populations. A strength of The Flinders Program was the emphasis on program tailoring to address a wide range of impacts and priorities identified in collaboration between the interventionist and the

survivor. The Flinders Program was not developed specifically for people affected by cancer, which was considered useful given the high and rising prevalence of comorbidity in this population. Further, it was not designed for a particular population and could be amended to suit different world views, which is important given the unequal impact of cancer on Māori. The third criterion related to the need for trained and accredited facilitators who could demonstrate key competencies and this was met by the program. The fourth criterion related to the ability of the program to be delivered one-on-one with whānau involvement and this was met. The final criterion was that it was foreseen to be able to be embedded in hospital-based care settings and this was also met by The Flinders Program. Before embedding the Flinders Program through a large multi-site intervention study, a mixed method pilot study was indicated in order to evaluate key components of acceptability and feasibility in NZ that could improve the feasibility of a larger study.

This phase two study pilots an intervention in a real-world setting to guide recommendations on whether to proceed to a subsequent phase three multi-site RCT (Beebe 2007; Prescott and Soeken 1989). The pilot took place at Wellington Hospital in two cancer clinic settings. The Flinders Program was administered on-site during standard clinical appointments.

This chapter describes the pilot study research design that was developed. It is presented in two parts. The first part of this chapter describes the pilot study aims and study design including methods for recruitment, randomisation, intervention, and assessment. The second part describes the results. The results relate to acceptability and feasibility of the study; as well as indicate the potential effectiveness of the intervention. The RE-AIM analytical framework is introduced and utilised.

Methods

This methods section describes the design of The Flinders Program pilot study, a phase two feasibility study. This study took place in hospital settings to address cancer care gaps reported by NZ cancer survivors.

The methods outlined in this section include descriptions of various adaptations that were incorporated into the study protocol as the study progressed to improve intervention

acceptability and feasibility in hospital clinic settings. The reasons for the specific adaptations will be explored in the results section.

Design, sample and setting

The Flinders Program was delivered in two ambulatory cancer treatment clinics at Wellington Hospital as part of a RCT feasibility study. An RCT pilot study design was utilised because it was deemed to be the most scientifically rigorous and efficient way to explore initial utility of the intervention and identify both potential benefits and adverse effects. It also provided a model for a larger phase three RCT, if indicated (Lancaster, Dodd, and Williamson 2004; Abbott 2014).

The overall study attempted to prioritise intervention acceptability and feasibility for Māori cancer survivors. The HEAT tool was used to assess The Flinders Program for its impact on health inequities (Signal et al. 2008). Adaptations were made to refine the intervention so it might be more responsive to Māori. For example, the intervention was delivered in NZ cancer clinic settings during standard clinic appointments. Therefore, it was available to everyone receiving treatment and did not require people affected by cancer to seek it out and opt-in. Adaptations also included addition of whakawhānaungatanga and inclusion of whānau.

Although The Flinders Program could be potentially valuable for any population affected by any cancer or long-term condition, the sample for this pilot study was limited to patients diagnosed with colorectal cancer. This cohort was chosen in order to limit heterogeneity in the sample and reduce case mix bias (Paddison et al. 2012). Additional reasons for selecting a colorectal cancer cohort included: 1) colorectal cancer is a very common cancer in NZ (Ministry of Health 2015a; World Health Organization 2008), 2) colorectal cancer intervention research is relatively underfunded considering relative disease burden (Carter and Nguyen 2012), 3) 70% of people diagnosed with colorectal cancer manage additional health complexity at diagnosis (Sarfati et al. 2009) and may benefit considerably from supported self-management intervention, and 4) there is an unequal burden on mortality by ethnicity for people diagnosed with colorectal cancer in NZ (Robson, Purdie, and Cormack 2010) so intervention with this cohort may contribute to reduction in inequity.

The setting for the study was Wellington Hospital. Wellington Hospital houses the regional Blood & Cancer Centre for people residing in the lower North Island and upper South

Island of NZ. In 2010, this facility treated approximately 2500 newly-diagnosed people affected by cancer (Cancer Control Council of NZ, 2010).

Recruitment

Potential participants were recruited from two ambulatory care clinics at Wellington Hospital, namely the oncology day ward and the surgical outpatient clinics. Consultations were held with health and supportive care workers from the recruiting clinics to obtain their views on the most feasible recruitment period for the study, considering clinic load and flow. Based on oncologists', surgeons' and nurses' estimates, an 8-12-month period of recruitment was planned to take place between May 2013 and May 2014.

The protocol specified a recruitment target of 30-50 patients, with half to receive the intervention and the other half to be designated the control group. The literature supported the sample size for pilot trials being typically determined pragmatically and no rules were identified for minimum numbers of pilot study participants needed to ensure a robust pilot study (Thabane et al. 2010). A pragmatic target of 30-50 total participants was agreed.

The implementation of the study was dependent on the goodwill and active participation of clinic staff at Wellington Hospital. Their enthusiasm was encouraging and critical to the success of the pilot. The recruiting oncologists, surgeons and nurses were briefed by the author. The study was to be introduced by recruiting clinicians who were provided with a brief script. It was to be introduced to colorectal cancer patients selected by them. Incentives provided to staff as recruiting clinicians included regular communication, via email and face-to-face, as well as update meetings where refreshments were provided. The recruiting clinicians agreed to discuss the study with potentially eligible patients and emphasise that the study was about improving survivorship care.

A recruitment referral form, entitled the *Authorisation to Release Information for Research Study Purposes*, was to be completed by the recruiting clinician for each patient that they informed about the study. The recruiters first provided each potential participant with a study overview, clinical trials pamphlet and a copy of the information sheet and consent form (see Appendices H & I). They explained that the study author wanted to meet with them to discuss the study if they were interested in participating. Potential participants were also told that the author provided a contribution toward their travel and time costs in the form of petrol vouchers. If the patient wanted to find out more, the *Authorisation to*

Release Information for Research Study Purposes form was to be signed by the patient (see Appendix J). That signature indicated that the patient consented to sharing their contact details with the author. A screening log was kept tracking study eligibility.

The author collected the signed recruitment referral forms from a secure drawer in the clinics. The referred patients were followed-up by telephone or at their next scheduled hospital appointment, depending on their indicated preference on the form. The author met with the potential participant, and whānau if present, and described the study in further detail. Most of these face-to-face meetings took place in a private room, such as the ‘family room’, within outpatient clinics. If the patient expressed an interest in participating in the study, he/she was provided with an information sheet (see Appendix H).

The patient was screened for study eligibility by the author. The eligibility criteria were determined by published protocol guidance (Battersby et al. 2010) and personal communication with Dr Anne O’Donnell, Wellington Blood & Cancer Centre clinic lead. These are shown in Figure 14.

The phase two study eligibility criteria were:

- Acknowledged primary colorectal cancer diagnosis being treated with surgery and/or adjuvant chemotherapy
- No apparent, or reported, physical or mental distress that would deem the trial to be overly burdensome
- No apparent, or reported, impaired ability to comprehend the intervention
- No history of taking part in Flinders or lay-led self-management programs
- Normally resident in Aotearoa NZ.

Figure 14: Eligibility criteria for the phase two pilot study

Eligible participants were asked to review and sign an informed consent form to participate in the study (see Appendix I). The participants were provided with a copy of the consent form for their records.

Once informed consent was obtained, a baseline assessment was scheduled with the participant. It was intended to take place at the next scheduled hospital appointment. The approximately 30-minute assessment consisted of self-report completion of a series of survey instruments (see Appendix K). At the time of assessment, vouchers were provided to study participants as a contribution toward their time and travel costs. At baseline assessment, a \$20 petrol voucher was given to the participant and at the follow-up assessment a \$30 voucher was provided.

Originally, the pilot was limited to patients of the outpatient day ward receiving chemotherapy treatment for colorectal cancer. However, recruitment proceeded slower than expected in the first three months at that clinic site with only five patients enrolled in that timeframe; 40% of the anticipated recruitment rate. In July 2013, recruitment and eligibility criteria were expanded to include patients receiving surgical colorectal cancer treatment through the main outpatient clinic.

Figure 15 shows the phase two study procedures and flow.

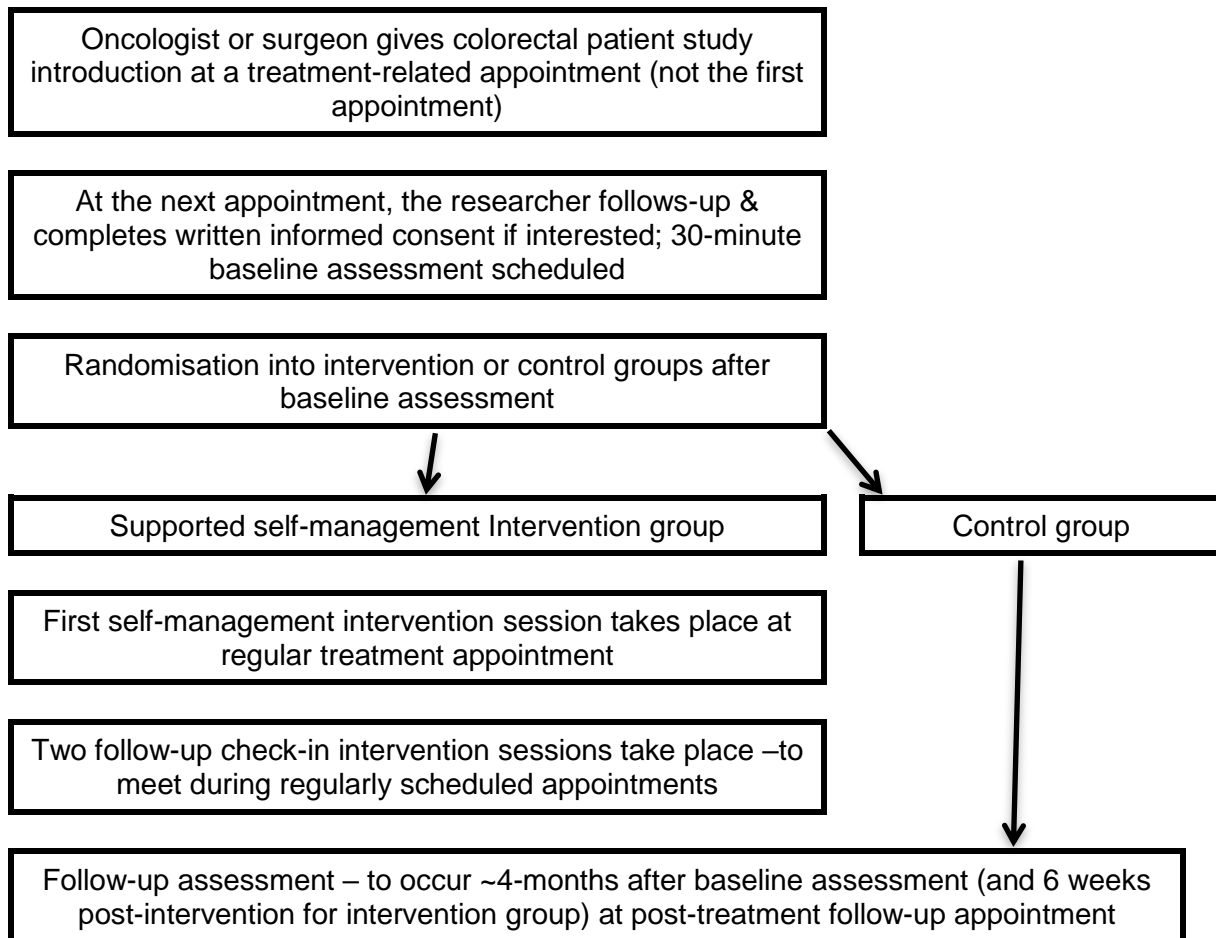


Figure 15: Phase two feasibility study flow diagram

Randomisation

Consenting study participants were randomly allocated to The Flinders Program three session intervention group or a standard supportive care control group. If the participant was randomly assigned to the intervention group, the intervention sessions took place at three regularly scheduled hospital appointment times. If the participant was randomly assigned to the control group, the researcher followed up with the participant at the treatment follow-up appointment. In the control group, standard supportive care by hospital staff was provided with no extra visits or intervention support. The people randomised to the control group received the standard medical and supportive care provided routinely to people receiving cancer treatment. Control group participants were informed that they would meet the researcher again at the treatment follow-up appointment.

Randomisation took place immediately following baseline assessment using a computer generated random number sequence. People were added to a list sequentially while the allocation sequence was concealed. The participants that were allocated odd numbers were placed in the control group and those allocated even numbers were assigned to the intervention group. All participants were told their group assignment directly after the baseline assessment was completed.

Intervention

The Flinders Program was delivered to those in the intervention group as a structured, professionally facilitated, tailored supported self-management program and care planning intervention. Intervention delivery took place at three standard clinic appointments attended by consenting study participants. These appointments occurred in the middle to late phase of a treatment regime (i.e. chemotherapy or surgical treatment).

Intervention sessions were planned to take place during appointment waiting times and sessions were timed to last no more than 30 minutes. All intervention sessions were convened by the author who was accredited to deliver The Flinders Program. Each session was based in collaboration between the interventionist and the study participant. The sessions were guided by the pilot study intervention protocol with field notes kept for each session.

The Flinders Program provided the framework to enable health and supportive care workers, and cancer survivors, to work together collaboratively and flexibly to address changing priorities and health needs. Sessions drew on a set of generic tools and processes tailored to inspire and enable increases in self-management competence for the participant. The intervention was adjusted for the NZ context. For example, a specific rapport building process to support meaningful participation and collaboration of participants was added. It specifically addressed whānaungatanga, identified as an important element of relationship building with Māori whānau. This component was added in response to recommendations from the phase one focus group work.

The toolbox of resources utilised for this pilot included goal setting worksheets, action plans, NZ patient experience DVDs, recommended internet sites, storytelling kits, and inspirational quotes. The session content was tailored based on intentional discussions around the personal life impact of cancer for the participant, life priorities in the midst of cancer, and collaborative problem-solving discussions to address values, barriers and goals. The author attempted to provide targeted support through culturally responsive interactions, using techniques such as active listening, reflection, and motivational coaching. If indicated, information resources were provided but the program sessions were intended as coaching sessions rather than information-delivery sessions.

At the first of three Flinders Program sessions, the author asked the participant to complete the Partners in Health scale. This one-page tool was completed independently. It asks the person to self-rate statements about their self-management capability such as “I take action when my symptoms get worse”, “I manage the effect of my health condition(s) on my social life” and, “I am able to deal with health professionals to get the services I need that fit with my culture, values and beliefs”. This is followed up by the Cue & Response Interview which clarifies through a collaborative assessment process the participant Likert scale ratings on the Partners in Health scale. It also checks assumptions held by healthcare practitioners about what the person knows and does to address wellbeing. Examples of interview topics discussed included relationships with whānau members, work and income concerns, and the impact of stress or fatigue. These discussions are underpinned by CBT and motivational processes. The tools foster further discussions around goals, action plans and enablers at the second session. Any agreed areas for addressing barriers and setting goals were recorded during and after this session on the Flinders Program care planning tools.

At the second session, a Problems & Goals Assessment tool was completed. This tool is a structured form that builds on the tools from the first session to guide discussion of factors that block or enable self-management. Enablers are then collaboratively identified and SMART goals set (Doran 1981). The documentation of SMART goals is aimed to enhance goal-setting in Specific, Measurable, Attainable, Relevant and Time-related ways. The three tools sequentially form the basis for intentional conversations leading to collaborative goal setting and survivorship/recovery care planning. A Flinders Care Plan was completed by the facilitator after the second session. The care plan included data collected from the assessment sessions, any amendments and some clinical data from the person's medical record. The care plan is where felt impacts, life priorities, goals, barriers and any strategies discussed were documented.

During the third intervention session, the session facilitator and the participant reviewed the completed Flinders Care Plan. The Flinders Care Plan consisted of both structured and tailored components that reflect strategies to meet collaboratively discussed priorities, needs and goals. Progress on strategies discussed in previous sessions were reviewed. Any additional strategies, information, goals and adaptations were able to be added to the care plan with coaching provided to support developing self-management competence in key areas. The supported self-management program sessions provided to intervention group participants as part of this pilot study culminated in development and review of personalised Flinders Care Plans for each person, including participating whānau.

Outcome measures

The outcome measures chosen reflect intervention acceptability, feasibility and utility. Acceptability was measured from process evaluation and surveys undertaken with intervention participants and recruiting clinicians. Feasibility was measured using process measures of intervention adoption and protocol implementation. Initial utility was measured with instruments that reflected intervention outcome or effectiveness related to intervention targets and effects.

Multiple measures exist to assess intervention-related constructs and outcomes of interest. There are many factors which can be used to choose outcome measures for a study. The factors considered for the choice of outcome measures were usability, reliability and validity.

Usability is one factor for consideration in choosing outcome measures. Assessment of measure usability includes consideration of respondent burden and ease of self-completion (Ugalde et al. 2015; Spinks et al. 2014). Respondent burden can be estimated based on the length of the instrument and the reported average time required for completion.

The psychometrics, specifically reliability and validity, are considered important considerations with regard to the choice of measures to be administered. Reliability and validity are terms used to describe the amount of error associated with a measures' ability to reflect the construct being measured. Outcome measure validity is a measure of how accurately an instrument measures what it is intended to measure while reliability is a measure of how consistent it is at measuring a variable (Balnaves and Caputi 2001). Validity and reliability of measures differ across populations (Scott et al. 2000; Frieling, Davis, and Chiang 2013).

Validity of studies can be internal or external. Internal validity refers to the extent to which the findings of the study are affected by random and non-random error, such as bias and confounding. External validity refers to the extent to which the findings of a study can be applied to populations other than that studied. Validity is also an important component of outcome measure psychometrics.

Reliability also relates to both studies and outcome measures. Study reliability refers to the repeatability of results. Instrument reliability refers to the ability of a measure to detect the true score in a given population, rather than any measurement error.

The RE-AIM analytical framework guided the presentation of outcome measure data. Each component of RE-AIM is described under individual sub-headings. Their application within this pilot study is clarified.

Reach

Intervention reach, in the RE-AIM context, reflects study participation. Study participation for this pilot study was portrayed using recruitment and retention data.

Effectiveness

Measures of effectiveness aim to determine the impact of the intervention and, in the construct of a feasibility study, inform recommendations on which measures to use for a larger-scale study. It is worth noting that the pilot data gathered for this study were not intended to achieve adequate power to prove intervention efficacy or utility due to the small anticipated sample size. The primary measures of effectiveness assessed self-efficacy while secondary measures were used to assess distress levels, quality of life, resilience and patient-reported experience of care.

Primary outcome measure: Self-management competence

The primary outcome measures of self-management competence were aligned with the construct of self-efficacy. Three measures related to self-efficacy were compared in this study. These were: 1) The Flinders Partners in Health scale, 2) The Stanford Program Chronic Disease Self-efficacy scale, and 3) The Patient Activation Measure. Each of these measures assess the concept of self-efficacy in that they relate to the confidence or motivation a person in managing aspects of their life, health and goals of care in the context of health conditions.

The Flinders Partners in Health scale was described as easy to use (Battersby et al. 2003). The measure validity and reliability were initially assessed by the developers and reported to be acceptable with construct validity shown and an internal consistency of 0.82 reported, exceeding the 0.75 Cronbach's alpha score considered minimum for an adequate measure of this aspect of reliability (Battersby et al. 2003). The PIH was originally developed as an 11-item self-report measure of chronic condition self-management (Commonwealth Department of Health and Aged Care 1999). In 2010, the scale was modified to a 13-item NZ version and administered to people with chronic conditions accessing primary care (Horsburgh et al. 2010). Each of the 13-items in the NZ version elicited a response on the sliding scale of 0 to 8 representing level of agreement with specific statements. The reported psychometrics show high usability, demonstrated construct validity and adequate internal reliability (Petkov, Harvey, and Battersby 2010; Smith et al. 2016). It takes approximately 5-10 minutes to complete.

The Chronic Disease Self-Efficacy scale was developed and tested for the Kaiser Permanente Chronic Disease Self-Management Program, now known as The Stanford Program. Developed in 1998, this easy to use 6-item scale (Lorig et al., 1996) was

administered as a point in time measure of self-management competence. The validity and reliability have been assessed with construct and criterion validity demonstrated and a high internal consistency score of 0.89 reported as reflecting adequate measure reliability (Lorig et al. 2001; Salvatore et al. 2015). The usability, reliability and validity of the scale has been shown to be high in numerous studies (Bodenheimer et al. 2002; Clark et al. 1991; Wilson 2008; Salvatore et al. 2015). It takes approximately 3-5 minutes to complete.

First published in 2004, the Patient Activation Measure was originally developed as a 22-item self-report measure to reflect motivation for self-management. This was later revised to a 13-item measure which is more commonly utilised (Hibbard et al. 2005). A conversion table translates the survey raw scores into a relative measure of activation level. Hibbard et al. reported that an increased self-rated activation score was predictive of increased self-efficacy and self-management competence (Hibbard et al. 2007). High levels of reliability and validity for the instrument have been demonstrated across populations (Lubetkin, Lu, and Gold 2010). Anecdotally, Flinders staff have found that Patient Activation Measure scores closely align with, and are reflective of, Partners in Health scale scores (Malcolm Battersby, personal communication, 2014). PAM has been used to indicate self-management support needs (Dixon, Hibbard, and Tusler 2009) as well as being used as an evaluative measure in research studies to assess the impact of supported self-management intervention on behaviour change (Fowles et al. 2009; Harvey et al. 2012). It takes approximately 5-10 minutes to complete.

Secondary outcome measure: Distress scale - Distress Thermometer (DT)

The Distress Thermometer is a single item visual analogue scale shaped like a thermometer with a numerical scale between 0 (no distress) and 10 (extreme distress) (National Comprehensive Cancer Network, Holland, and Bultz 2007). Respondents are asked to circle the number on the thermometer that best describes their level of distress over the last week. Several studies indicated a cut-off score of 4-5 as having optimal sensitivity to detect clinically significant levels of psychopathology (Dolbeault et al. 2008; Gessler et al. 2008; Graves et al. 2007; Ransom, Jacobsen, and Booth-Jones 2006; Tuinman, Gazendam-Donofrio, and Hoekstra-Weebers 2008). Smaller numbers of studies recommended higher or lower cut-off scores. The Distress Thermometer contains a complementary problem list that asks respondents to tick boxes to indicate areas where problems exist in practical, familial, emotional, physical, or spiritual domains. This

instrument has been used in a growing number of studies overseas (Patel et al. 2011; Zabora et al. 2001; Roth et al. 1998). It takes approximately 8-15 minutes to complete.

Secondary outcome measure: Quality of Life (global) SF-12v2

Quality of life is a complex construct with no agreed definition in the literature. Quality of life in cancer is generally accepted as a sense of wellbeing across the physical, psychological, social and spiritual aspects of life (Ferrell 1996). For this study, a generic quality of life measure was chosen for administration because it was recommended in the Battersby protocol for administration of The Flinders Program (Battersby et al. 2010). The SF-12v2 was the specific measure identified and recommended for use in the protocol guidance published by the Flinders Program founder (Battersby et al. 2010). The SF quality of life measures are internationally validated, have proven psychometrics and are widely respected and used (Ware and Sherbourne 1992). The SF-12, a shortened version of the original SF-36, was revised in 2002. The SF-12v2 quality of life measure was chosen for this study because it is short and usable while retaining adequate reliability and validity as a global quality of life measure across different population cohorts (Ware et al. 2002). It takes approximately 10 minutes to complete.

Secondary outcome measure: Resilience scale - Connor-Davidson Resilience Scale (CD-RISC)

Resilience is a concept that describes adaptability and response to stress or trauma (Seville 2008). For this study, the shortened version of the full 25-item CD-RISC measure (Connor and Davidson 2003) was administered. The 2-item CD-RISC (Vaishnavi, Connor, and Davidson 2007) asks the person to self-rate how true these statements are for them, “I am able to adapt when changes occur” and “I tend to bounce back after illness, injury or other hardships”. These statements reflect perceived adaptability to stress. Summary scores range from zero (indicating low resilience) to eight (indicating high resilience). The literature describes the instrument as having convergent and discriminant validity with a Cronbach’s alpha score of 0.89 (Yu and Zhang 2007). In a general population survey, the mean CD-RISC 2 score was reported as just under a score of seven (Vaishnavi, Connor, and Davidson 2007). It takes approximately 1 minute to complete.

Secondary outcome measure: Patient experience – 2009 NZ Cancer Care Survey

The 2009 NZ Cancer Care Survey was used as a measure of patient experience. The original survey was adapted from the internationally utilised National Research

Corporation and Picker Institute (NRC+Picker) ambulatory oncology instrument (NRC 2005) which had already been slightly modified by researchers who used the survey in New South Wales (NSW), Australia (Heading et al. 2009). The survey consists of 96 questions on many aspects of the cancer journey including diagnosis, treatment (surgery, chemotherapy and radiotherapy), symptom management, healthcare team, care environment and overall impressions of care. The baseline data from the first administration of the survey in NZ did not include assessment of measure validity and reliability with a NZ survivor cohort. No follow-up patient experience studies have been conducted in NZ. Administration of this survey in this study will enable comparison to the original baseline data. Although this measure has low usability due to its length, and no psychometric assessment to report, it is conceived to be a useful addition to the assessment package because of its NZ-specific baseline data. It is interesting to explore whether inclusion of a supported self-management intervention compared to standard supported care, impacts on the patient experience in any particular domains. The literature indicates that there is an association between patient experiences of care and person-centred care outcomes (Delnoij 2009; Paddison et al. 2012; Watson et al. 2005.; Zimlichman, Rozenblum, and Millenson 2013). Supported self-management programs emphasise collaboration between patients and clinicians to achieve optimal outcomes. It would be useful to see if supported self-management intervention impacts on patient experience.

Most survivorship studies incorporate multiple measures to evaluate intervention outcome as standard practice. Table 7 provides an overview of outcome measures used in the feasibility study. The choice of outcome measures was experimental and based on published Flinders Program protocol guidance (Battersby et al. 2010). Additional measures of self-efficacy were included for comparative purposes. The distress measure was included because versions of this measure are in routine use in some NZ cancer clinics. The patient experience survey was included because it provides a source of NZ baseline data in a relevant area.

Table 7: Overview of outcome measures used in the feasibility study

Self-reported outcomes of interest	Instruments	Usability criteria (item # and time to complete)	Response options
Demographics	Patient Information on study consent	6 items 3-5 minutes	Fill in the blanks
Self-efficacy	Partners in Health scale (Petkov, Harvey, and Battersby 2010) Chronic disease self-efficacy scale (Lorig et al. 1996; 2001) Patient Activation Measure (Hibbard et al. 2004)	13 items 5-10 minutes 6 items 5-10 minutes 13 items 5-10 minutes	Likert-type scale of self-management capability rated from 0 (poor) to 8 (very good) Likert-type scale rated from 0 (not confident) to 10 (very confident) 4-response Likert-type scale rated from strongly disagree to strongly agree
Distress	Distress Thermometer (DT) (National Comprehensive Cancer Network 2013)	Thermometers & Problem List 8-15 minutes	Circle response & tick boxes on problem list
Quality of Life	SF12v2 (Greenfield, Kaplan, and Ware 1985; Frieling, Davis, and Chiang 2013; Cheak-Zamora, Wyrwich, and McBride 2009)	12 items 5-10 minutes	Multiple choice
Resilience	CD-Resilience scale (RISC) (Connor and Davidson 2003)	2 items ~1 minute	Self-complete 4-response Likert-type scale rated from strongly disagree to strongly agree
Patient experience	2009 Cancer Care Survey (O'Brien et al. 2010)	97 items 45-60 minutes	Multiple choice

Adoption

Adoption was defined as the feasibility for carrying out The Flinders Program in the NZ hospital setting. It was indicated in this study by process data from field notes on actual intervention delivery, timing and setting.

Implementation

Implementation describes the extent to which a program or study is delivered acceptably and as intended. This was shown by data from a satisfaction survey as well as process data.

Satisfaction was measured in both study participants and recruiting clinicians. The instruments used to measure study satisfaction in this study were adapted from a survey developed in NZ. This survey had been used to measure the acceptability of a guided self-help brief intervention in general practice to address sub-threshold mental health syndromes (Collings et al. 2012). Study participants in the intervention group rated their satisfaction with the intervention around nine statements (Collings et al. 2012). The survey asks the person to self-rate statements about their intervention satisfaction such as “I am satisfied with the self-management support sessions I received”, “I found the sessions helpful” and, “I would recommend these sessions to a friend.” Statements are included to assess satisfaction with the length and number of sessions provided. Figure 16 shows all nine statements included in the follow-up assessment for intervention participants. Clinician satisfaction with the intervention was assessed based on responses to a subset of four statements chosen from the patient satisfaction measure as seen in Figure 17 (Collings et al. 2012).

Further contributing to implementation evaluation was process data. Process data was obtained from a screening log, randomisation log, and The Flinders Program care planning tools. Protocol deviations, barriers and enablers were identified and analysed from this documentation.

1. I am satisfied with the self-management support sessions.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2. I found the sessions helpful.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3. The sessions were long enough.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4. There were enough sessions.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5. I felt the person working with me was interested in me as a person.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6. I was able to make useful changes with the help of the sessions.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7. The changes have improved the way I am feeling.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8. I am confident that these changes will be lasting.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9. I would recommend these sessions to a friend.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

Figure 16: Survey questions used to assess study participant satisfaction with the intervention

1. I thought the supported self-management intervention was acceptable in the hospital/outpatient clinic setting.	Disagree Strongly	Disagree	Neither agree nor disagree	Agree	Agree Strongly
2. The supported self-management intervention seemed to meet some of my patients' needs.	Disagree Strongly	Disagree	Neither agree nor disagree	Agree	Agree Strongly
3. It was easy to refer patients to the supported self-management intervention.	Disagree Strongly	Disagree	Neither agree nor disagree	Agree	Agree Strongly
4. I would like to see supported self-management intervention made available to patients again.	Disagree Strongly	Disagree	Neither agree nor disagree	Agree	Agree Strongly

Figure 17: Survey questions used to assess clinician satisfaction with the intervention

Maintenance

Maintenance was not assessed in this pilot study. It refers to the extent to which a program has become embedded and changes sustained in the longer term. This was out of scope for the feasibility study undertaken and reported on in this thesis.

Table 8 shows a summary highlighting the four of five RE-AIM elements addressed in the context of the phase two Flinders Program feasibility study. More information on RE-AIM can be found in Chapter three.

Table 8: Summary of the RE-AIM framework as it relates to phase two The Flinders Program feasibility study

RE-AIM framework outcomes	Methods	Data collection tool
Reach: The absolute number of participants who participate in a given program	Number of participants Drop-outs Representativeness of participants	Baseline demographics % consenting % participating % drop-out Process documentation
Effectiveness/Efficacy: The impact of an intervention on important outcomes	Self-efficacy Quality of life Distress Resilience Patient Experience	Partners in Health scale, Patient Activation Measure, Chronic disease self-efficacy scale SF12v2 Distress Thermometer CD-RISC 2009 NZ Cancer Care Survey
Adoption: The setting, timing and context for delivery. This outcome is for the intervention component of the study.	Intervention location Intervention delivery	Process documentation
Implementation: The extent to which a program or study is delivered as intended.	Intervention satisfaction Care plan review Protocol deviations Barriers and enablers identified	Satisfaction measures - Participant - Clinician Flinders care plan audit Process documentation

Assessment of outcomes

The outcome measures were administered to study participants by the author or one of two research assistants. The author was the study interventionist. In light of potential social desirability and acquiescence bias, follow-up assessments for all intervention participants were undertaken by research assistants.

Prior to an assessment session, the assessor ensured that screening and informed consent processes had been completed. The baseline assessment was stated to take approximately 30 minutes and consisted of: 1) standard demographic questions utilised by the Ministry of Health for the NZ Health Survey (Statistics NZ 2011); 2) instruments to measure self-efficacy, distress, quality of life, and resilience (see Table 7); and 3) three open ended questions about life impacts of cancer and coping strategies.

The follow-up assessment was conducted in person at the 6-week post-treatment follow-up appointment. The assessment was estimated to take about 75 minutes. The follow-up assessment included the same surveys as participants had completed during the baseline assessment, with additions of a measure of patient experience and intervention satisfaction. Five qualitative open-ended questions were added to obtain further information on intervention acceptability and utility. The participant was sent home with the patient experience survey to complete and mail back in a pre-paid self-addressed stamped envelope if it could not be completed at the appointment due to time constraints.

Analysis of data

The phase two pilot study empirical data included process documentation, field notes, outcomes data from survey instruments and a care plan audit. Process documentation relied on study forms and field notes. Outcomes data, including demographic data for consenting participants, were recorded on the consent form and survey instruments. The care plan audit was based on completed care plan forms. All forms were stored in a secure location in folders labelled with participants' study numbers.

Data were treated in different ways. Process data were recorded, summarised and reported. Assessment data were entered into an MS Access database by one research assistant (Appendix M contains full outcomes data sets for key patient-reported outcome measures). Entries were quality checked by the author. Data were exported to MS Excel.

Data files were imported into STATA and R for analysis. Scoring instructions accompanying the registered use of the data collection tools were referenced to guide scoring, calculation of average scores, and subscale reporting. Simple descriptive and univariate between group analyses were performed on baseline demographic and outcome measure data. Further analyses on the small data set was not attempted because of the low numbers, corresponding to low power, and large confidence intervals which would preclude any conclusions being drawn.

It was originally planned that data would be analysed on two levels: intention-to-treat and “as-treated”. However, the small sample size and withdrawal of only one participant part-way through the study, meant that the practical decision was made to analyse only the complete data sets excluding data from the single withdrawn participant.

Results

This feasibility study evaluated the acceptability, feasibility and initial utility of The Flinders Program to improve survivorship care.

Reach (Sample)

The reach of the intervention reflected the study sample. Recruiting clinicians controlled study access. Between May 2013 and October 2014, thirty-three people in total were referred to the study and twenty-eight consented to participate. Those who did not consent refused mainly due to poor health or feeling already overwhelmed by cancer and its treatment. The majority of total referrals were from the Wellington Blood & Cancer Centre (n = 23). The flow of participants during the course of the study is presented in Figure 18.

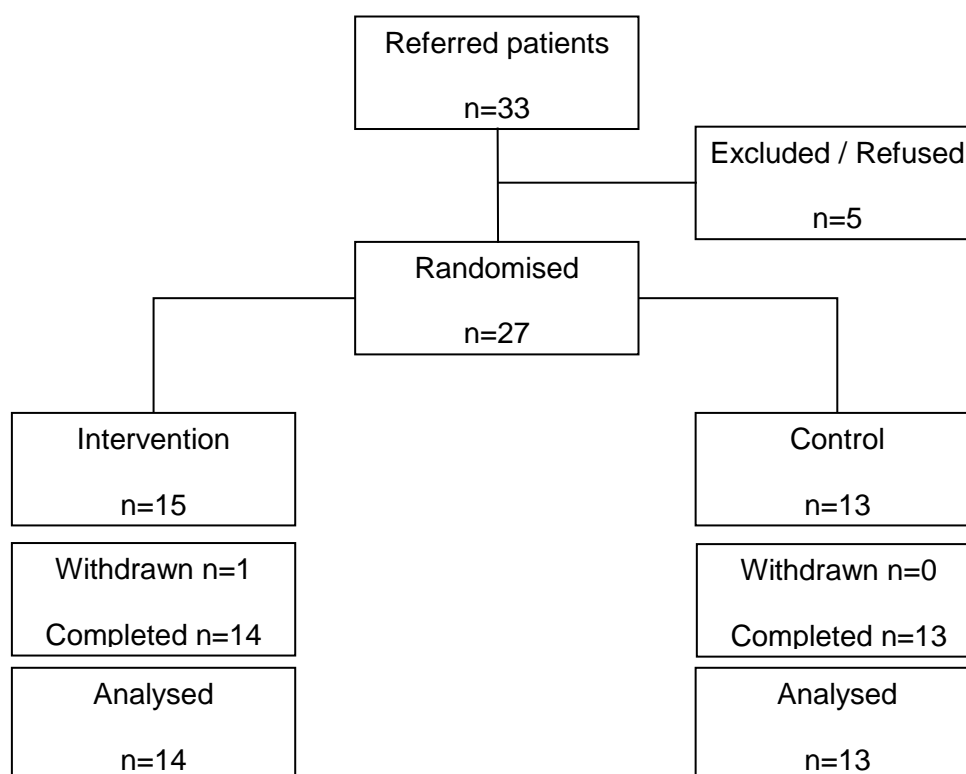


Figure 18: Flow of participants during the course of the pilot study

Originally, the field component of the study was estimated to last a total of 12-months. This comprised an 8-month recruitment period and approximately 4-months of follow-up for each study participant. The recruitment target was two subjects enrolled per week resulting in 50 subjects recruited over 25 weeks. A margin of error was built into this rate calculation to allow for holidays, staff leave and other disruptions, hence the proposed 8-month recruitment period.

However, due to slower than expected recruitment rates, the recruitment procedures required adaptation during the pilot study. In order to address recruitment challenges, the study lead began to meet regularly with the clinical leads to review recruitment progress and discuss recruitment options. The first option suggested by a clinic lead was that the patient list be reviewed each week to identify and flag potentially eligible patients. This pre-screening method did not substantially impact on the study referral rate. The next strategy to boost participation and reduce inclusion criteria confusion was to expand recruitment eligibility. The recruitment referral form (in Appendix J) was simplified in July 2013 to indicate that all patients “with a confirmed diagnosis of colorectal cancer” were eligible for referral to the study. The eligibility criteria were also adapted and the words ‘outpatient chemotherapy’ were removed so that all patients receiving treatment for colorectal cancer

met the eligibility criteria, not just those receiving chemotherapy. In August 2013, recruitment was expanded to include the main outpatient surgical department. The surgical nurse was an enthusiastic study champion and recruited patients to the study. This resulted in increased study referrals. Recruitment ended in July 2014. Although recruitment did not reach the anticipated number of 50 patients, the data gathered from the 27 participants who completed the study provided key insights into study acceptability and feasibility.

Downstream recruitment barriers did not seem to be related to identification of potential participants but more to do with recruiting clinician priorities which included time pressure and judgements about patient suitability for the study that determined who heard about the study. With regard to time pressure, recruiting clinicians inferred that important clinical issues needed to be addressed first meaning little time was left to introduce the study. This was identified as a source of bias in the study.

Randomisation procedures

The randomisation procedures worked well and resulted in a relatively even distribution of patients in the intervention and control groups in terms of demographic and clinical characteristics as seen in Table 9. The demographic characteristics of the 27 subjects who completed the study in the intervention and control groups are reflected through frequencies and percentages for the categorical variables of gender, ethnicity and age. These can be compared to the demographic characteristics of all NZ cancer registrants with a first-time diagnosis of colon cancer from the year 2008, the most recent year for which data is currently available (Ministry of Health 2015a).

The representativeness of the study participants was broadly similar to the demographics of colon cancer registrants in NZ in 2008 (Ministry of Health 2015a) in gender, ethnicity and age. The majority of participants were 60 years of age or older (85%) which closely aligns with the demographics for those diagnosed with colorectal cancer. More males (59%) than females participated in the study and colorectal cancer is more common in males in NZ. Further, study participants were more likely to be Māori (in keeping with the study priorities) than would be expected from the comparative national data. However, the study cohort was closely representative of those identifying as Māori in NZ, which is approximately 15% of the population. Māori are under-represented in registrations for colorectal cancer compared to non-Māori. Although not shown in the table, 70% of

participants in this study had diagnosed comorbidities recorded in their electronic health record.

Table 9: Comparison of study groups with all 2008 colon cancer registrants

Variables	Intervention group (n = 14)		Control group (n = 13)		All colon cancer registrants in NZ 2008 (n = 2801)*	
	Frequency	%	Frequency	%	Frequency	%
Gender						
Male	9	64.3	7	53.9	1441	51.4
Female	5	35.7	6	46.2	1360	48.6
Ethnicity						
Māori	2	14.3	2	15.4	121	4.3
Non-Māori	12	85.7	11	84.6	2680	95.7
Age					Two studies have reported the mean age of diagnosis in NZ to be 70 (Cunningham et al. 2009; Murray et al. 2011)	
30-39	1	7.1	1	7.7		
40-49	1	7.1	1	7.7		
50-59	2	14.3	2	15.4		
60-69	7	50.0	5	38.5		
70-79	1	7.1	2	15.4		
80-89	1	7.1	2	15.4		
90-99	1	7.1	0	0		

* Ministry of Health, 2015

Effectiveness

The primary goal of this sub-section is to report on the usability of several instruments as outcome measures for intervention studies. There was insufficient power, due to low-participant numbers, to warrant in-depth interpretation of this data. Individual-level analyses reported are indicative of potential areas of interest for future inferential analyses in larger studies.

In this sub-section, the pre- and post-assessment survey results are presented for the intervention and control groups. Baseline assessment took place mid-way through a phase of cancer treatment. Post-assessment took place at the 6-week follow-up appointment. This represented assessment of short-term outcome only. Observations related to

instrument usability are also presented. Scores for all primary and secondary measures for each participant, except for the patient experience survey, are available for review in Appendix M.

The tables shown in this sub-section show the mean and standard deviation of the data. The higher the standard deviation, relative to the scale, the larger the variability in scores between individuals. The accompanying box plot figures are also shown to allow for a better visual sense of the comparative distributions between intervention and control group data. Boxes represent the data within the interquartile range from the 25th to 75th percentile. The lines or whiskers extend to encompass the full range of the data.

Self-efficacy: primary outcome measure

Three self-efficacy measures were compared: the Partners in Health Scale, The Patient Activation Measure and the Chronic Disease Self-efficacy Scale.

Each of the 13 –item Partners in Health scale statements were rated by participants on a scale of 0 to 8 where 0 indicates low self-management competence and 8 indicates the highest competence. Each item related to a different aspect of self-management competence. When these statements are analysed at single item level, 58% (8/14) of intervention participants scored one or more of the 13-items as 4 or below at baseline assessment. 31% (4/13) of control group participants scored one or more items as 4 or below at baseline assessment. Scores of 4 or below indicates low perceived self-management competence in that area. Table 10 shows the counts of items with scores of 4 or below at baseline compared to follow-up for intervention group participants.

Table 10: Partners in Health scale counts of items with scores of 4 or below for intervention group participants

Intervention group Participant ID	Number of items scored at 4 or below at baseline	Number of items scored at 4 or below at follow-up
01-112-51	0	2
01-114-51	1	3
01-115-51	0	4
01-117-51	9	9
01-119-51	0	3
01-118-51	10	1
01-120-51	3	1
01-123-51	0	0
01-124-51	0	0
01-132-51	2	0
01-134-51	8	0
01-136-51	1	1
01-139-51	0	0
01-140-51	13	0

Given the small number of participants, it is not possible to discern any clear pattern in the results. A small increase in overall reported self-management competence was identified in the intervention group follow-up scores where 58% (8/14) of intervention participants scored one or more items at 4 or below. However, the individual participants scoring items at 4 or below differed between baseline and follow-up. In other words, some people who reported high levels of self-management competence in certain areas at baseline reported lower self-management competence in certain areas after the intervention.

A small increase in overall reported self-management competence was also identified in control group participant follow-up scores where only 15% (2/13) of control participants scored one or more items at 4 or below. Once again, the individual participants scoring items at 4 or below were seen to differ by individuals between baseline and follow-up.

Table 11 shows the counts of items with scores of 4 or below at baseline compared to follow-up for control group participants.

Table 11: Partners in Health scale counts of items with scores of 4 or below for control group participants

Control group Participant ID	Number of items scored at 4 or below at baseline	Number of items scored at 4 or below at follow-up
01-113-21	0	0
01-125-21	1	0
01-126-21	0	0
01-127-21	1	0
01-128-21	0	0
01-129-21	0	0
01-130-21	0	1
01-131-21	0	0
01-133-21	2	0
01-135-21	1	0
01-138-21	0	0
01-141-21	0	6
01-142-21	0	0

Partners in Health scale means and standard deviations are shown in Table 12. The average scores showed little change between baseline and follow-up assessment. More variability in overall change scores is seen in Figure 21 with intervention group scores ranging above and below the median.

Patient Activation Measure mean scores for intervention and control group participants were similar at baseline. However, the mean scores diverged at follow-up by group. Scores indicated increases in self-efficacy and activation across both groups. However, the control group showed greater increase in patient activation mean scores between baseline and follow-up. Variability in change scores, as demonstrated in the box plots shown in Figure 19, were broadly similar in interquartile range spread between the control

and intervention groups with large variability seen. Again, small numbers mean that these results are not likely to be representative.

The Chronic Disease Self-efficacy Scale means and standard deviations were more similar at baseline than at follow-up assessment. The mean confidence scores for the intervention group decreased while scores increased in the control group. The box plots show large variability in change scores for both the groups.

Two representations of the resulting scores from the three self-efficacy measures administered and compared in this study are shown in Table 12 and Figure 19. Table 12 identifies the mean and standard deviation for combined intervention and control group scores. It also shows the mean and standard deviation of the change over time.

Table 12 highlights a consistent variation between control and intervention group change scores. The baseline self-efficacy assessment measures' mean scores for people in the control group were higher than those reported at baseline in the intervention group. Figure 19 does not show any consistent variation in scores.

Table 12: Self-efficacy measure scores (means and standard deviations)

Outcome measure	Study group	Baseline assessment Mean (SD)	Follow-up assessment Mean (SD)	Change
Partners in Health scale	Intervention	6.2 (1.5)	6.5 (0.7)	0.3 (1.4)
	Control	6.9 (0.7)	7.1 (0.9)	0.2 (0.6)
Patient Activation Measure	Intervention	59.8 (15.7)	64.2 (14.5)	4.4 (17.5)
	Control	62.6 (8.8)	72.1 (15.2)	9.5 (11.8)
Chronic disease self-efficacy scale	Intervention	6.8 (1.8)	6.5 (1.8)	-0.3 (2.0)
	Control	7.4 (1.0)	8.0 (2.1)	0.6 (2.0)

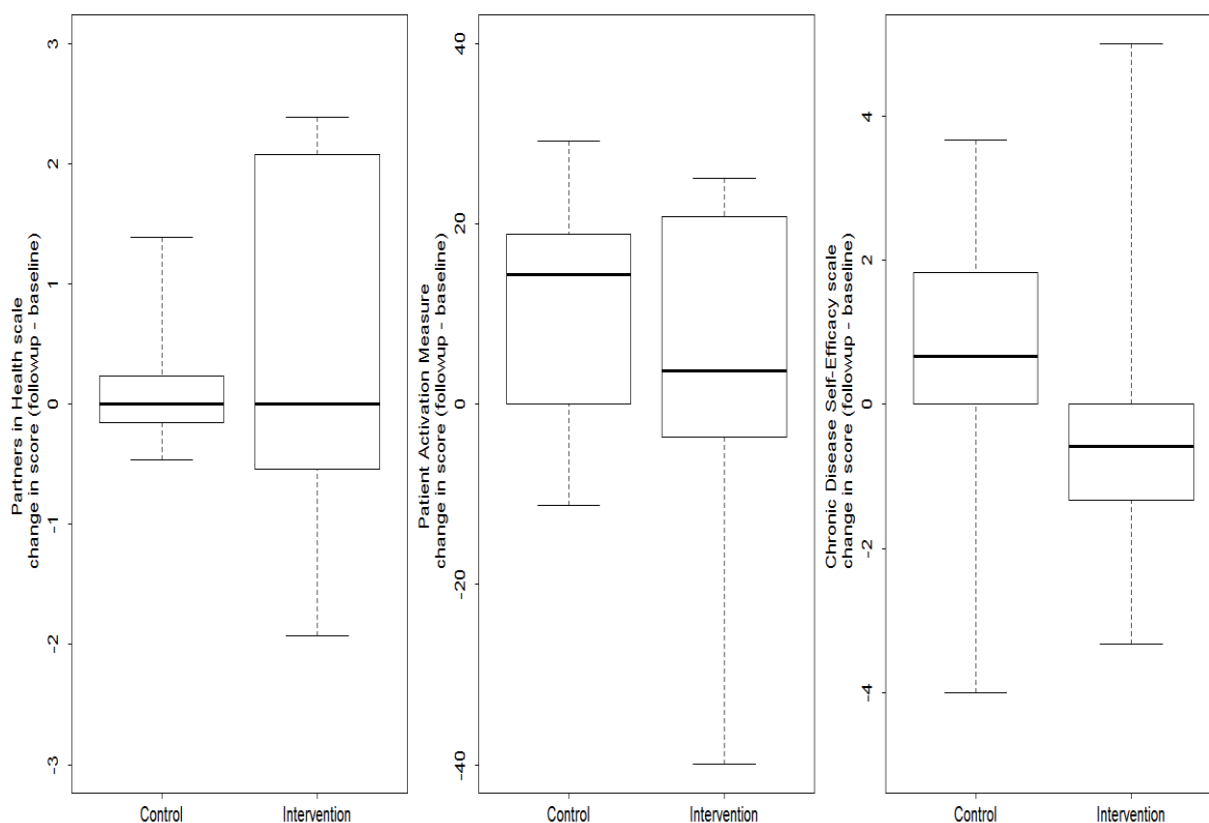


Figure 19: Change in self-efficacy score distributions between baseline and follow-up assessment (medians and ranges)

Quality of life SF12v2: secondary outcome measure

The SF-12v2 results were calculated for the mental and physical health components of global quality of life health and wellbeing. The scores were computed into the norm-based physical health component score (PCS) and the mental health component score (MCS). The summary scores show decreases in global quality of life between baseline and follow-up for the intervention group across both physical and mental health scores. Small increases in mean scores over time can be seen for the control group. SF12v2 mean average scores are shown in Table 13.

Table 13: SF12v2 scores (means)

Outcome measure	Study group	Baseline assessment	Follow-up assessment	Change
		Mean	Mean	
Physical health component score (PCS)	Intervention	38.5	30.8	-7.7
	Control	50	52	2.0
Mental health component score (MCS)	Intervention	52	47.1	-4.9
	Control	49	52	3.0

Distress and Resilience

Distress Thermometer combined means were higher for the intervention group at baseline assessment and this pattern continued at follow-up assessment. Average scores and standard deviations are shown in Table 14. The means for both groups showed a similar slight downward trend from baseline assessment to follow-up assessment resulting in the same mean and median change score. There was more variability identified in the intervention group change scores over time. For two people in the intervention group, distress scores greater than six were reported at baseline and those scores dropped to three at follow-up assessment. Conversely, one person in the intervention group reported a score of two at baseline which rose to eight at follow-up. Although, individual variability in scores was noted there were no major changes in scores noted for the control group participants.

Resilience scale combined means for the groups were between six and seven out of eight. The means diverged between baseline and follow-up for the intervention and control groups. The intervention group showed a decrease in mean resilience score (-1.0 change score) over time while the control group showed an increase in mean resilience score (0.4 change score). The variability in change over time scores for both groups was fairly similar overall although it extended mainly above the median for the control group and below the median for the intervention group.

The calculated means and standard deviations as well as change scores for the distress and resilience scales are shown in Table 14 and Figure 20.

Table 14: Distress and resilience scores (means and standard deviations)

Outcome measure	Study group	Baseline assessment Mean (SD)	Follow-up assessment Mean (SD)	Change
Distress scale (DT)	Intervention	2.9 (2.9)	2.7 (2.6)	-0.2 (3.4)
	Control	1.8 (2.4)	1.6 (2.2)	-0.2 (2.2)
Resilience scale (CD-RISC)	Intervention	6.4 (1.8)	5.5 (2.2)	-1.0 (2.2)
	Control	6.9 (1.4)	7.3 (1.2)	0.4 (0.9)

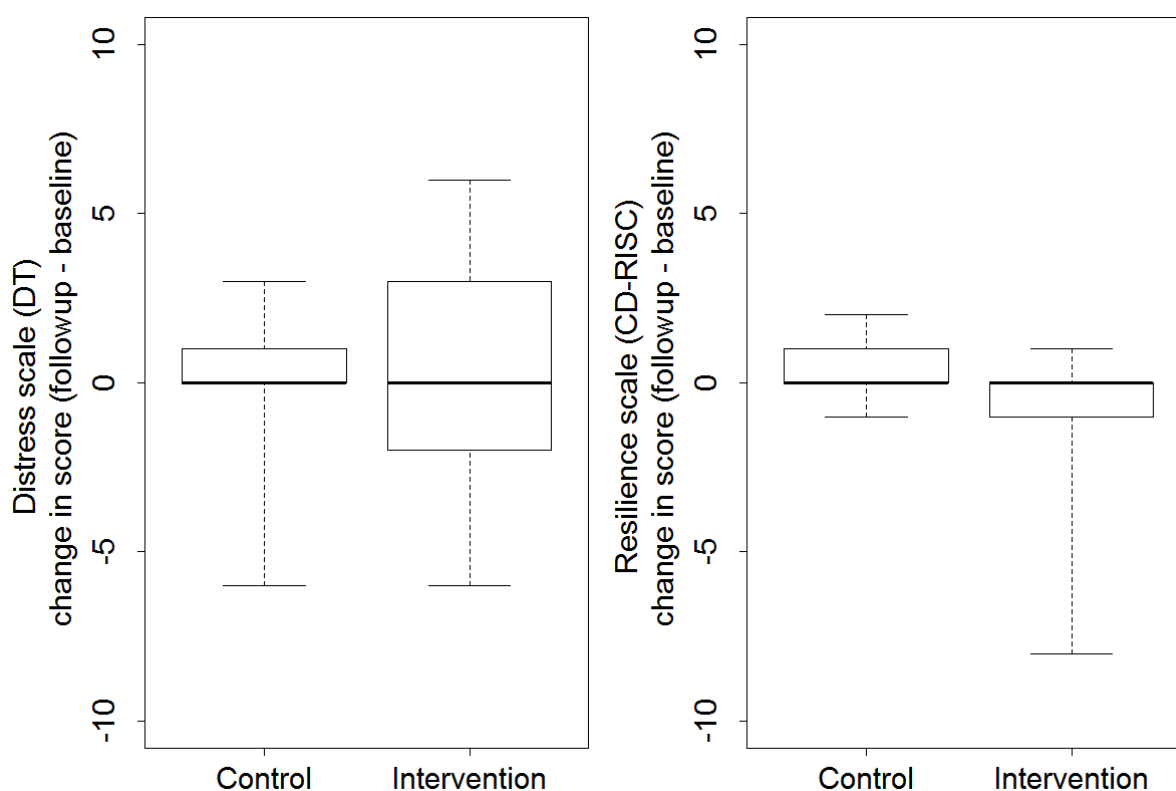


Figure 20: Change in distress and resilience score distributions between baseline and follow-up assessment measures (medians and ranges)

Patient experience measure

The Cancer Care Survey results from pilot study participants were compared to baseline data collected in the national survey administered in 2009 (Cancer Control Council of NZ, 2009). In the analysis only the 'ideal' response, such as "always" or "definitely", was equated with a positive experience. Confidence intervals were included with the baseline data from the original survey but these were not calculated for the small data set from this study as these intervals would likely be very large and uninformative in this context.

A subset of participants chose to complete this survey at home with eight respondents from the intervention group (57%) and ten respondents from the control group (77%) returning it completed. All 18 respondents (100%) indicated that the overall quality of all cancer care received over the last 12-months was excellent, very good or good. This is similar to the score of 97% of patients who rated cancer care at this level in the 2009 Cancer Care Survey administration.

Areas of strong performance and opportunities for improvement reported in the original Voice of Experience report (Cancer Control Council of New Zealand 2009) were compared with results for intervention and control groups in this study. Table 15 shows that results varied significantly from baseline data across both study arms.

Table 15: Original key strengths of cancer care, highlighted by the percentage of high score responses > 85% to the 2009 Cancer Care Survey.

Aspects of care	Intervention group % positive response	Control group % positive response	2009 Baseline % positive response (CI)
Coordination of care	63	75	91 (90-93)
Ease of understanding directions/signs	63	80	90 (89-92)
Level of privacy provided	38	80	87 (85-89)
Dignity and respect provided	88	100	86 (85-88)

Table 16 shows scores for intervention, control and baseline on aspects of care that baseline respondents from the 2009 Cancer Care Survey were least positive about. These were identified as opportunities for improvement.

Table 16: Original key cancer care opportunities for improvement, highlighted by the percentage of scores < 50% in response to the 2009 Cancer Care Survey.

Aspects of care	Intervention group % positive response	Control group % positive response	2009 Baseline % positive response (CI)
Providing enough information on:			
Relationship changes	60	50	32 (29-35)
Sexual activity changes	60	33	31 (28-34)
Emotional changes	63	63	39 (36-42)
Providing explanations for treatment waiting times	25	50	34 (30-37)
Putting patients in touch with care providers to help with anxiety and fear, if this was required	40	0	36 (33-39)
Taking living situation into account	13	50	49 (46-51)

The results for aspects of cancer care that represented key strengths and opportunities for improvement were outlined in the original Cancer Care Survey report. When these are compared to the data from this phase two study, the data indicates that the control group had higher percent positive scores in the aspects of care identified as strengths of cancer care from the baseline survey. Results were, for the most part, lower in the aspects of care originally identified as opportunities for improvement. However, scores were variable across intervention and control groups with regard to opportunities for improvement with no discernable pattern.

Intervention experiences were also addressed in this study using open-ended questions (see Appendix L). The purpose of the qualitative component of the pilot study was to explore patients' experiences of cancer life impacts, support and the intervention. These three main topics were assessed with qualitative open-ended questions as part of the follow-up assessment. This contributed to data on burden and benefit from study participation. Both system and person-related barriers impact on intervention acceptability and feasibility.

Participants were asked about the same topics addressed in the phase one study, namely their experience of life impacts of cancer, effective coping strategies and their views on supported self-management intervention. With regard to life impacts of cancer, responses reflected similar multidimensional and holistic social, physical, emotional and spiritual themes reported in the phase one study. A noted difference was that most of the participants receiving treatment, stated that they were looking forward to treatment end so they could move forward, one person described it as “forget the year”, and get on with life or work. Other unique perspectives included one person who reported feeling shunned at work during treatment while another stated that it was “extraordinarily difficult to try to deal with the concept of a shortened life span”. Participants identified support or coping strategies that they found helpful which included rest, working to routine, whānau support and meditation. Programs accessed by two individuals included home help, counselling, and Cancer Society courses. The intervention was identified as useful by all participants who completed the three-session Flinders Program. One person reported that it was “helpful to be reflective” while another found benefit in action plans.

There were a few recommendations shared for how the experience could be better. One person from the intervention group stressed the importance of communication and coordination across departments. Another intervention group participant wondered if the supported self-management sessions could take place via Skype. In summary, participants in the study reported that cancer did impact on their lives in many ways and that support with coping strategies and recovery was considered useful.

Adoption

Data for this sub-section was sourced from process documentation related to the adoption of the intervention and adaptations for the setting.

The adoption of the intervention was impacted by appointment timing. The intervention sessions were to be undertaken during regular hospital clinic appointments. The variable waiting times meant that the logistics of meeting sometimes entailed multiple visits by the study lead to meet the participant for a session.

The timing of the intervention was established based on recommendations by the clinical advisory team. Clinical advisors were instrumental in designing this study.

Although the focus group participants were asked about timing of the intervention, no clear consensus was reached on the most appropriate time, so the recommendation of the clinical advisory team was to administer the intervention mid-way through a phase of treatment. It was envisioned that the timing of the three intervention sessions would be similar for every participant. However, in practice, there were some differences in when people received their first intervention session. For example, for some people it was at the third appointment and for others the sixth. The sessions took place at variable clinic appointments. Many occurred prior to a standard clinical appointment and some during chemotherapy delivery. Sometimes sessions took place during unplanned hospital admissions for complications or post-surgery. It was difficult to achieve a standard procedure because of the variability in appointment keeping. However, a key reason for choosing this intervention was flexibility in intervention delivery.

The intervention sessions ranged in duration from 15 to 90 minutes with a median duration of 29 minutes. The duration of the intervention sessions was impacted by appointment priority, whereby the intervention was stopped when the clinical appointment began. The duration of the intervention sessions seemed appropriate and 85% of the sessions lasted under one hour. Therefore, the total time needed for the full intervention, delivered over three sessions, was approximately one and a half hours.

Barriers to planned intervention session delivery included unplanned hospitalisations, changed appointments and various health status factors. Although all participants did receive three sessions during their treatment phase, sometimes these were conducted outside the established routine when people were at hospital for various other reasons.

All intervention participants collaborated in development of a survivorship care plan (see example in Appendix N). An audit of completed care plans identified various priority issues and goals discussed collaboratively between the consenting participant and the author. The care plan issues or goals which were most prevalent for the 14 participants related to relationships, combating fatigue, participation in active recovery, and employment. These issue or goals are shown in Table 17.

Table 17: Top Flinders Care Plan issues or goals reported by study participants

Identified care plan issues or goals	Prevalence
Improve whānau relationships	10/14 = 71%
Build strength and stamina	9/14 = 64%
Pursue active post-treatment recovery/survivorship	9/14 = 64%
Find or return to work	7/14 = 50%
Support others going through colorectal cancer	2/14 = 14%
Advance care plan for future health events	2/14 = 14%
Move house/fix up house	2/14 = 14%
Travel or revive hobbies	2/14 = 14%
Cope better with low mood	1/14 = 7%

Actions identified from these collaboratively identified issues and goals ranged from establishing regular family get-togethers to a stepped return to work plan. The most common action listed in the care plan incorporated SMART goals for undertaking regular exercise. Example actions discussed specifically to address the most prevalent goal (i.e. to improve whānau relationships) included: holding regular family meetings, accessing counselling sessions, hosting a celebratory meal, planning a holiday, or developing a whānau inclusive advanced care plan.

Bias may have been introduced by the examples provided by the author in relation to actions. The author did comment that other people have suggested actions of specific types to give the participant a sense of action planning. Further, actions proposed by participants are likely to have associations with demographic characteristics but this was not explored further in this pilot study.

Implementability

The implementability of the intervention addressed study processes as well as stakeholder experience and satisfaction. Process data were reviewed to inform study enablers and barriers as well as protocol deviations required to administer assessment and intervention sessions. A satisfaction survey was administered to intervention group participants and clinicians to assess study experience.

A key barrier to study implementation was recruitment. Recruitment processes were an area where enablers and barriers were apparent. Recruiting clinicians included oncologists

and surgeons, clinical nurse specialists and clinic nurses. These individuals varied in their recruitment success. For example, nurse recruiters achieved better recruitment rates than oncologists and surgeons. Recruitment barriers within the hospital setting were identified in two main areas. Firstly, recruiting clinicians had limited time with patients and needed to prioritise clinical requirements over introducing the study. Secondly, when the study did get presented, recruiting clinicians anecdotally reported that many eligible patients did not wish to participate in the study. Based on verbal reports of the recruiting clinicians and nurses, the main reasons for patients refusing participation were: wanting to focus just on treatment at that time, not knowing how supported self-management could help, or no interest in taking part in research. These reasons were not documented, although the participant referral form did request this information. Consequently, a determination of the feasibility of achieving, for example, a 70% recruitment rate for eligible patients, was not able to be assessed. Lack of process data on recruitment rate was identified as a barrier in this study.

It was unclear if the clinicians understood and explained to patients the balance between potential intervention benefit compared to additional burden during treatment. Reasons reported by patients for choosing study participation included: wanting to help others, appreciation of extra support, or wanting to take advantage of any opportunity to ensure treatment success.

It is recommended that more effort be put into establishing standardised recruitment pathways to help clinicians present the study to potential patients as well as providing materials to enable the study to be described in ways that support participation. Recruiting clinicians were asked to record information on those who could not be referred or refused referral to the study. This was not feasible. Anecdotally, some clinicians mentioned that they had talked to one or two patients about the study but had received negative responses. Clinical judgement calls were also made by the clinicians on whether that patient would be able to take in the study information at that time. One clinician stated “I introduce the study to patients who could use some love”.

The majority of patients who did hear about the study and met with the study lead, enrolled in the study. The randomisation to group worked well. Although patients who signed the consent form were made aware that there was a 50% chance of being assigned to the control group, some were disappointed about their assignment. The study team did discuss making the intervention available to control group participants post-treatment, but

the logistics of this suggestion prevented this. The intervention could have been delivered by phone or appointments made at an alternative location, but this was not undertaken due to complexity in delivery and time constraints for the study. Nevertheless, it was recommended that this opportunity be made available for participants in subsequent studies.

The attrition rate for study participants was low with just one person withdrawing from the study part-way through due to poor health, complex family pressures and failure to realise immediate benefit from study participation. That person's data were not included in any analyses. It would be expected that attrition would be higher if the recruitment rate were higher, if the intervention had lasted over a longer period of time, or if longer-term outcomes were measured post-treatment.

Engagement with study advisors and clinical staff was another area of focus. Study advisors provided advice critical to addressing issues that arose. Advisors were approached during meetings for the C3 studies or individually as needed. Clinical staff were approached, at first, through scheduled brief meetings that were scheduled at specific intervals (i.e. monthly). Then, engagement occurred individually at opportune moments in the ward or clinic.

Intervention delivery was a third area of focus. Flexibility in meeting changing appointments and health needs, as well as the need to address support person participation, were adaptations required for intervention delivery. Waiting times for appointments or treatments did present opportunities to carry out study procedures. However, there was always a time pressure and unknown around how much time was available for sessions. Sometimes appointments were adjusted as unanticipated hospitalisations and appointment changes occurred affecting participation.

Adjustments were made to incorporate whānau who attended the appointments with the study participant. Whānau participation was not assumed. If a support person accompanied the study participant to the clinical appointment where an intervention session was scheduled, a discussion about taking part in future sessions was broached. The research participants were also asked privately, if feasible, if they wanted their whānau to take part in future sessions. If agreed by the participant, whānau were asked to participate in the intervention session and be included as a named participant in the Flinders Care Plan documentation.

Outcome assessments were carried out at baseline and follow-up. Particularly problematic was administration of the follow-up assessment. This was envisioned to take place at the standard 6-week follow-up appointment but it was rarely able to be completed in the timeframe of prior to or after that specific appointment which tended to be of short duration and run to schedule. Therefore, for 80% of participants, the follow-up assessment was completed in part at the clinic and in part at home.

The second component of intervention implementability was satisfaction. A satisfaction survey was administered to most intervention group participants and referring clinicians. 87% (13 out of 15) of intervention group participants responded to the survey. Four out of nine (44%) recruiting clinicians responded to the satisfaction survey.

100% of intervention group respondents reported high levels of satisfaction (score >3.5 out of 4) with the supported self-management intervention program. All respondents reported that they would recommend these sessions to a friend. 92% (12/13) of respondents reported that they agreed or strongly agreed that the self-management support sessions were helpful. The same percentage agreed that there were enough sessions and that these were helpful and long enough. The majority (85%) strongly agreed that the intervention felt highly person-centred with the other two respondents agreeing with this statement. However, many intervention group respondents disagreed that the intervention improved the way they were feeling (46%) or that they would be able to make lasting changes from the intervention (46%).

Four out of nine clinicians (44%) responded to the clinician satisfaction survey. Scores indicated that some aspects of the intervention program were more acceptable than others. All four of the clinician respondents agreed or strongly agreed that the intervention program was acceptable in the outpatient clinic setting. Three out of four agreed or strongly agreed that it could address some patient needs (75%) and was easy to access (75%). Two agreed that they would like to see the program made available to patients again.

Process measures were also reviewed to assess implementability of the intervention. Although participants and health practitioners identified the survey processes to be acceptable, issues were identified during the study which may indicate that the intervention is not suitable for all cancer patients. For example, cognitive impairment was identified as a barrier to intervention suitability. One participant was identified by his oncologist as likely experiencing cognitive impairment, a relatively common side-effect experienced in

conjunction with some cancer treatments. The assessment data showed no change in any outcome measures from pre- to post-assessment. This finding may indicate that need for intervention suitability assessment. A screening tool might be useful to determine future intervention suitability and readiness.

Intervention mapping

Intervention mapping is recommended as best-practice in intervention planning and delivery. Intervention mapping involves planning program delivery based on information from the target population (Kilbourne et al. 2007), the literature and any pilot research. Bartholomew et al identifies five steps: (1) creating a matrix of proximal program objectives and outcomes, (2) selecting theory-based intervention methods and practical strategies, (3) designing and organizing a program, (4) specifying adoption and implementation plans, and (5) generating program evaluation plans (Bartholomew, Parcel, and Kok 1998). Intervention mapping is a stepwise approach for theory and evidence-based development and implementation of interventions (Bartholomew et al. 2006; Bartholomew, Parcel, and Kok 1998; Kok et al. 2004; Michie et al. 2008). An intervention mapping exercise was undertaken using the stepped approach including creating a matrix of proximal program objectives and outcomes. This matrix or map is shown in Figure 21. It visually displays the proposed intervention effects and outcomes considered. Figure 21 shows the proposed interaction of the person, cancer and treatment relating to the person, whānau and the environment but also taking into consideration cancer-related symptoms and side-effects. Proximal, or short-term, intervention targets were identified from the literature review and studies presented in this thesis. Intervention targets were included in the phase two study were resilience, distress, self-efficacy, quality of life and patient experience. No gold-standard process or clinical outcome measures were identified from the literature. Further, the phase two study indicated less utility for using the specific patient experience survey as an outcome measure. An intervention map reflects best-practice. It can be updated, based on study data, to reflect more specific target outcomes and the working map is shown in Figure 21.

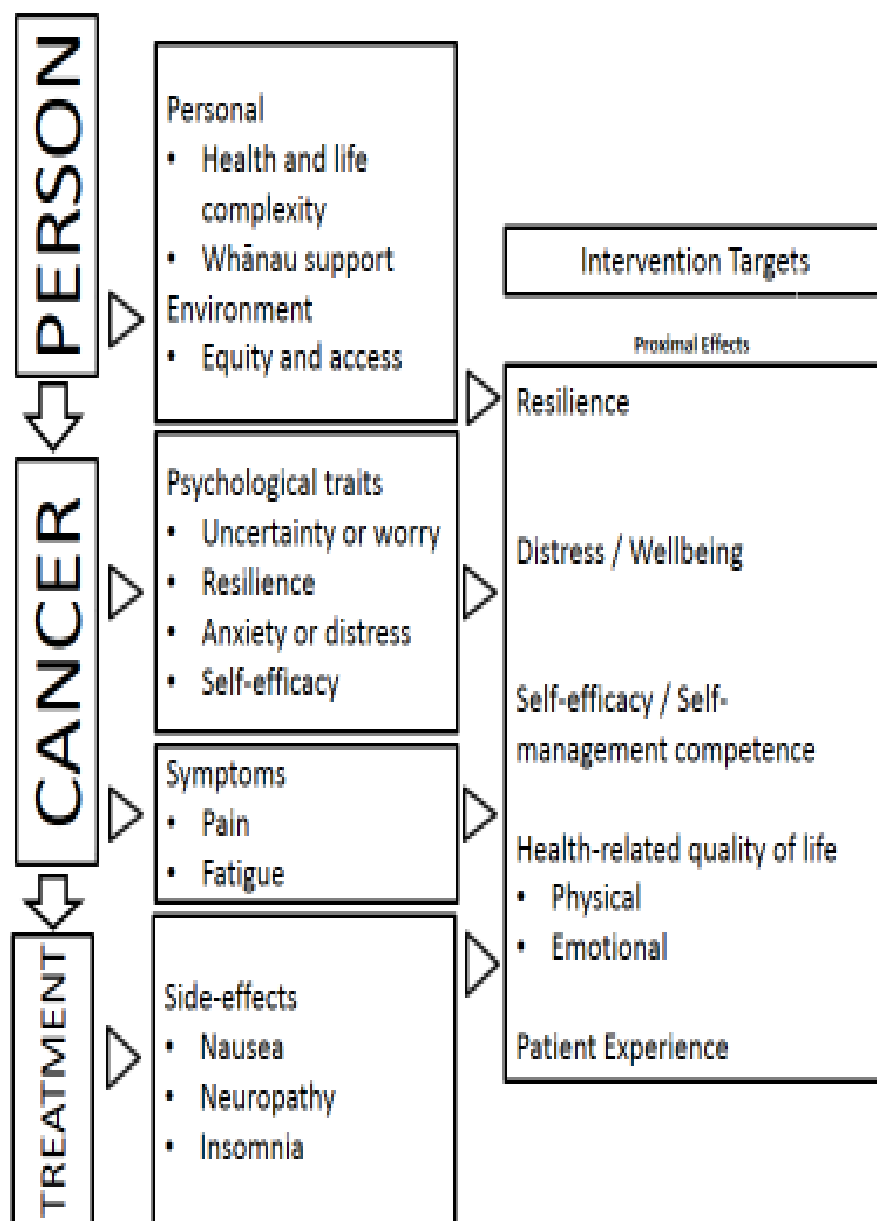


Figure 21: Intervention mapping incorporating study data

Chapter summary

The phase two pilot study evaluated acceptability and feasibility of conducting a supported self-management intervention program in hospital-based cancer care settings. The study was administered utilising a pre- and a post-assessment design to explore outcomes of interest for intervention and control groups. This study met its objectives by generating data that addressed acceptability and feasibility of the program.

The MRC framework recommends a phase two pilot study as an iterative step to progress a well-designed intervention study (MRC 2009). The feasibility study design considered three components of acceptability and feasibility for conducting a trial: 1) recruitment and randomisation of enrolled participants; 2) an intervention and control group; and, 3) a pre-post assessment design. The specific aims of this exploratory pilot study were to assess the acceptability and feasibility of a study design for a supported self-management intervention program, tailor intervention delivery to ensure fidelity, explore useful outcome measures and recommend next steps to inform a decision on whether to pursue a well-powered, multi-site phase three cancer survivorship clinical trial. The quantitative pilot study provided descriptive insights into study feasibility.

Supported self-management was able to be piloted and results reported effectively using the RE-AIM framework. In applying the framework, reach was the term used to outline the sample recruitment and retention data. Effectiveness was shown by data from outcome measures which, albeit underpowered, did not suggest obvious intervention effectiveness. Adoption was addressed by review of study processes as well as enablers and barriers to delivery of the intervention in hospital settings. Implementability was reflected in study process review as well as satisfaction survey results from intervention group participants and recruiting clinicians. Table 18 summarises the key findings across the five RE-AIM elements deemed important for study evaluation.

Table 18: Key result findings reported using the RE-AIM framework

RE-AIM framework	Pilot findings
Reach: The absolute number of people who participate in a given programme	<p>Acceptability measures:</p> <p>Number of final participants = 27; a lower than ideal recruitment number</p> <p>Participants were representative of cancer-affected population in ethnicity and age. More females chose to participate in the study.</p> <p>Drop-outs = 1; points to intervention acceptability</p>
Effectiveness: The impact of an intervention on important outcomes	<p>Utility indicators generated data to enable exploration of:</p> <p>Self-efficacy – all measures usable</p> <p>Quality of life – high usability; results reflect population norms</p> <p>Distress – high usability; little change in score noted over time</p> <p>Resilience - high usability; little change in score noted over time</p> <p>Patient experience – low usability; similar results to 2009 survey for those who did complete the survey</p>
Adoption: The absolute number and representativeness of setting and interventionist.	<p>Feasibility measures:</p> <p>Intervention location in hospital clinics was acceptable but less feasible</p> <p>Intervention delivery varied and required flexibility</p> <p>14 care plans developed with prevalent issues identified in areas of relationships, fatigue, active recovery and work.</p>
Implementation: The extent to which a programme is delivered as intended.	<p>Protocol deviations recommended and required</p> <p>Single site, two clinic, single interventionist delivery</p> <p>Staff involved had variable contributions and hugely impacted on recruitment and delivery</p> <p>Study participants and clinicians agreed that they were satisfied with the intervention in the short-term</p>
Maintenance: Sustainability	Not assessed in this pilot

To the extent it was able to be evaluated, the intervention appeared to be acceptable for Māori. The phase two study enrolled two Māori participants in each arm of the study. For both intervention group participants, whānau were interested and able to be involved with the intervention.

A randomised sample was indicated for the phase two study because there is little evidence to show supported self-management program intervention utility in NZ, specifically with a cancer survivor cohort. Intervention and control groups worked well. Once patients were enrolled in the pilot study, procedures for random assignment to intervention or control group were adequate. In both groups, some participants had higher scores at follow-up, while others had lower scores and some showed no change over time. The decrease in feelings of wellbeing reflected by the low follow-up scores may reflect an unintended consequence of the intervention. Small sample size could account for these differences; however these results need further exploration.

This study results suggest there is a complex mix of enablers and barriers for delivery of supported self-management program intervention in NZ. It showed that conducting pilot intervention research within the NZ clinical setting is important because modifications to proposed protocols are necessary. The unforeseen challenges encountered in this feasibility study can inform protocol modifications to improve future study fidelity.

The focus of this study was on supported self-management program intervention acceptability and feasibility. The intervention was evaluated as acceptable by most participants and recruiting health and supportive care workers involved in the provision of care impacted by intervention. With regard to implementation feasibility, the following issues were documented as needing to be addressed further :1) the need for functioning and appropriate referral pathways, 2) pre-screening and regular follow-up screening of patient and survivor readiness to engage with self-management, and 3) availability of outcome measures of areas impacted by supported self-management intervention programs validated in survivor populations.

From the key factors of acceptability and feasibility, acceptability of the intervention was indicated on a survey completed by recruiting staff and study intervention participants. Feasibility for progression to a phase three trial was questionable based on barriers identified and concerns for fidelity. An RCT would be indicated if feasibility issues could be addressed. It may be logical to conduct a second feasibility study testing updated procedures, in the cyclical fashion suggested by the MRC guidance, prior to conducting a full-scale multi-site RCT.

CHAPTER 6: Discussion

‘If we knew what we were doing, it wouldn’t be research’ (Unknown)

Cancer is common, unevenly distributed and rising in prevalence for New Zealanders. The mortality rate has decreased and cancer survival is on the rise (Ministry of Health 2015a). In order to improve care for cancer survivors, redesigned care pathways are needed to enable provision of better quality survivorship care across NZ (Sarfati, Koczwara, and Jackson 2016; Jackson 2016). This study contributes research to inform survivorship care pathway development and redesign.

The studies described in this thesis specifically explore survivors’ experiences and the acceptability and feasibility of supported self-management program intervention to address unmet needs and cancer care gaps reported in NZ. The results point to significant physical, emotional, social and spiritual impacts due to living with, through or beyond cancer in NZ. Supported self-management was shown to be an acceptable, but a questionably feasible, intervention program to address these impacts in the hospital-based cancer outpatient clinic during treatment.

A summary of the full findings is first presented. Then, the phase one and phase two combined results are integrated with published data to address the research questions. The second section considers the strengths and limitations of the study design and data. Finally, implications and recommendations for practice and future research are suggested.

The objectives of the qualitative phase one study were to:

- Qualitatively explore, with survivors and health professionals, cancer treatment impacts, life and health complexity, as well as management strategies utilised by NZ cancer survivors during and post-treatment; and,
- Use an intervention vignette to gauge the perceived acceptability of The Flinders Program, a supported self-management program, in the NZ hospital-based cancer clinical setting.

The objectives of the quantitative phase two study were to:

- Test study design aspects of recruitment, randomisation, intervention delivery and assessment by linking in with clinical flow in ambulatory cancer care clinics;
- Provide insights into intervention content as well as identify enablers and barriers of key aspects of intervention delivery;
- Explore and compare outcome measures of self-efficacy; and, measures of global quality of life, distress, resilience and patient experience.

Summary of findings

Survivorship is an area of growing concern and research in NZ and overseas as more people affected by cancer live with, through and beyond cancer-related impacts. This study explored supported self-management intervention as an approach to address the unmet needs of cancer survivors. In brief, supported self-management intervention programs aim to inspire and empower people to acquire and practice skills to carry out different medical regimens and lifestyle changes as well as to navigate social, physical, emotional and spiritual impacts associated with chronic condition treatment and recovery.

The key theoretical models guiding the studies exploring survivors' experiences and supported self-management program intervention presented in this dissertation were Durie's 1994 Te Whare Tapa Wha Māori health model, Wagner's 1996 Chronic Care model and the 2012 descriptive cancer survivorship framework by Klimmek and Wenzel. Each phase of the research structure and methods presented were informed by the revised MRC guidance on complex interventions (MRC 2009). Phase one qualitative data were presented thematically using a Framework Analysis (Srivastava and Thomson 2009) and phase two quantitative data were presented categorically using the RE-AIM framework (Glasgow et al. 2001).

The key findings from the phase one study were:

- Cancer survivor impacts were experienced across physical, emotional, spiritual and social domains. Impacts were intermittent and persisted over the long-term.
- Impacts needed to be self-managed, in part, alongside day-to-day life challenges and health complexity related to other conditions.

- Survivors' life and health complexity management strategies aligned to Klimmek and Wenzel's (2012) characterisation of cancer survivorship work. Different types of work were prioritised for different individuals and population groups.
- Survivors identified supported self-management program intervention as a promising area for further research but did not want it to replace any existing supports.

The key findings from the phase two study were:

- A supported self-management program was piloted and results reported using the RE-AIM framework.
- The intervention was acceptable to most participants and health and supportive care workers involved in the provision of care impacted by intervention. Whānau were interested and able to be involved with the intervention.
- The intervention had questionable feasibility for delivery in the treatment setting. To embed supported self-management intervention effectively into the existing care pathways during treatment, the following issues need to be reconsidered:
 - Functioning and appropriate referral pathways with clinical champions that assist colleagues to comply with study protocols including adverse event reporting and documentation of those who decline to participate;
 - Addition of pre-screening, risk stratification and regular follow-up screening of patient and survivor readiness to engage with self-management;
 - Use of outcome measures validated in survivor populations that can be assessed both in the short-term and longer-term. Further consideration of robust and validated clinical process and outcome measures.

Insights into the research questions

In this section, data will be integrated between the studies presented in this thesis and the literature to address the research questions.

Durie's (1994) Te Whare Tapa Wha Māori health model was a good fit to describe the impacts reported by cancer survivors in this study. Social, physical, and emotional impacts

were clearly described by NZ cancer survivors in the literature. There was a more limited literature base on spiritual impacts. Differences were noted in reported experiences shared in this study with some people describing impacts in one area while others described impacts across areas.

Wagner et al.'s Chronic Care Model (1996) was used as a guide to inform research into redesigned cancer care pathways that incorporate survivorship. Supported self-management is an integral component of this Model. The evidence from the literature indicates that supported self-management programs deliver modest improvements in variable outcomes of interest. Evidence in the cancer literature was found to be minimal. Nevertheless, supported self-management was considered to be an intervention identified and recommended for further research. It was envisioned as able to address cancer-related and comorbidity impacts through boosting individual self-efficacy alongside collaborative development of tailored strategies to strengthen relationships with whānau, health and supportive care workers, and communities.

The purposes behind the first two research questions were to: 1) ascertain how cancer impacts were experienced by NZ cancer survivors, and 2) explore how survivorship impacted on QOL, if at all, in NZ. The ways NZ survivors self-managed any impacts was also documented.

What and how are cancer impacts experienced by survivors in NZ?

There is a limited body of existing literature describing the experiences of NZ cancer survivors (Doolan-Noble et al. 2006; Egan et al. 2014; Hutt Valley DHB et al. 2006; O'Brien et al. 2010; Walker et al. 2008). However, there exists a substantial body of international literature describing cancer survivor experiences (Coulter 2006; Heading et al. 2009; Henry et al., 2008; Jefford et al. 2008; Kennedy et al. 2007; Little et al. 1998; Ohlsson-Nevo et al. 2012). The phase one study contributed data to fill the gap in the literature around survivorship impact for Māori and non-Māori New Zealanders.

In the phase one study, people described the impact of cancer in different ways. Diagnosis was experienced as a shock and treatment was associated with impacts that lingered. This is congruent with the international literature that showed treatment and survivorship are associated with adverse physical and psychological impacts to varying degrees (Earle and Neville 2004; Hewitt, Greenfield, and Stoval 2006; Jefford et al. 2008; Koczwara 2015;

Richardson et al 2011). Life after cancer treatment was described as both hopeful and frustrating which is congruent with other overseas research (Lakdawalla et al. 2012). The finding of persistent and intermittent cancer impacts for New Zealanders post-treatment aligns with previously published reports from both qualitative and quantitative cancer survivor experience studies (Egan et al. 2014; O'Brien et al. 2010).

The recognised emotional, social and spiritual impacts of cancer and other chronic conditions on Māori wellbeing have been previously documented in NZ (Dew et al. 2015; Slater et al. 2013; Walker et al. 2008). Kidd et al. (2013) described these undiscussed emotional, social and spiritual impacts that impacted on wellbeing as part of the reason why addressing health needs was perceived as *whakāma* for Māori. Embarrassment prevented Māori from openly discussing health and wellbeing with healthcare practitioners because safe topics were seen to be related to physical health issues, while other areas of health-related impact were not raised (Kidd et al. 2013). The data collected in this study added to the international literature by showing that cancer treatment impacts described in focus groups seemed to differ somewhat by ethnicity. In general, Māori participants' narratives included greater integration of the emotional, social and spiritual impacts of cancer while the non-Māori participant narratives were characterised by a focus on the physical impacts of cancer treatment. These varying emphases placed on the emotional, social and spiritual aspects of cancer by Māori focus group participants were consistent with the predominant holistic wellbeing-based Māori health philosophies described by Durie (1994, 2012) and Pere (Pere 2005) as well as Pasifika health philosophies (Fotu and Tafa 2009).

Cancer treatment impacts were described by focus group participants as intermittent and unpredictable over time. This also describes survivors' experience of the landscape associated with modern-day cancer treatment (Moorcraft, Smyth, and Cunningham 2013; Aklilu and Eng 2011; El-Amm and Aragon-Ching 2013). In the phase one study, participants reported experiencing difficulties with treatment side-effects that lingered into post-treatment. This result is like that described by Hewitt et al. (2006) in their review of the literature on the transition from cancer patient to cancer survivor. The authors described managing treatment and managing post-treatment as equally challenging for survivors (Hewitt, Greenfield, and Stoval 2006). The challenges associated with treatment have been shown to last many years for some. Research from the UK has indicated that 64% of colorectal cancer survivors report ongoing health problems five to seven years after diagnosis (Macmillan Cancer Support 2011; Wells 2011). Phase one data pointed to

the need for further clarity on referral options or sources of support for these intermittent impacts that affect survivor wellbeing.

Cancer was referred to in the 2016 NZ Health Strategy, for the first time, as a long term condition (Minister of Health 2016a) lending authority to the chronic nature of cancer experienced and described by survivors. However, there is ongoing debate about this classification and whether it does justice to the very different experience of cancer survivors to those who manage other long-term conditions (Tritter and Calnan 2002).

What else contributes to life and health complexity for NZ cancer survivors?

The integration of cancer treatment with everyday life contributed to reported life and health complexity of study participants. Participants in the phase one study described the multiple impacts cancer and cancer treatment had on wellbeing. Wellbeing was impacted during treatment by varying levels of fatigue, unpredictable emotions and various other problems. These impacts were most often managed outside the treatment setting (Hewitt, Greenfield, and Stoval 2006). The need to manage treatment impact outside of the clinical setting aligned with reports from the literature (Klimmek and Wenzel 2012). Focus group participants discussed dealing with cancer-related impacts in many aspects of their lives. They described how they tried to self-manage impacts or seek helpful advice from whānau or other community members. These findings align with the results reported in Egan et al.'s 2014 Cancer Stories Project. The Cancer Stories Project identified important factors that helped people cope with cancer. Specifically, the authors identified that coping strategies utilised were often “wrapped around the concept of empowerment” (Egan et al., 2014, p. 94). In this study, the phase one focus group participants described seeking health practitioner support as a last resort; most participants first tried to manage physical, emotional, social and spiritual impacts on their own or with strategies supported by whānau. The practice of self-management is already common for New Zealanders, but data indicated that it could be better supported by health and supportive care workers.

Comorbidity was identified as contributing to health complexity for survivors in both the phase one and phase two studies. Cancer and comorbidity often coexist (Sarfati, Koczwara, and Jackson 2016). Data from the 2006/7 NZ Health Survey indicated that two out of three New Zealanders live with a long-term health condition (Frieling, Davis, and

Chiang 2013). Approximately 70% of the pilot study participants in the phase two study had comorbidities recorded in their electronic health record. This finding directly aligns with data from other NZ studies that identified comorbidity as common in people affected by cancer (Sarfati, Koczwara, and Jackson 2016), with research specifically identifying high-levels of comorbidity prevalent in colorectal cancer survivors in NZ (Sarfati et al. 2009). Life and health complexity is compounded by living with, through or beyond cancer according to the study data.

Can supported self-management approaches help address cancer and comorbidity impacts for survivors?

The research presented in this thesis suggests that a supported self-management intervention program may help address cancer and comorbidity impacts for some survivors. It is not a one-size fits all solution.

Multiple recommendations have been made for further research into supported self-management as a promising approach for survivorship intervention (NHS Improvement 2013; Sarfati, Koczwara, and Jackson 2016; Minister of Health 2016a). However, there has been no research on this approach in NZ cancer-affected populations published to-date nor sufficient conceptualisation of why or how this particular approach should actually bring about a sustained change in survivor wellbeing in a given setting (Boger, Demain, and Latter 2013).

A main weakness associated with supported self-management as a complex intervention is that the theoretical underpinnings and mechanisms of action related to this type of program are diffuse (see Chapter three for more on this topic). This research did not answer the question of 'how' supported self-management intervention impacts on outcomes. One proposed hypothetical mechanism of action for supported self-management programs is that this complex intervention approach acts as an environmental mediator that may counteract or mediate negative impacts on wellbeing associated with cancer treatment (Parkhurst 2013). Supported self-management intervention, as an environmental mediator, may provide a 'safety net' of resilience that helps prevent treatment opt-out or breakdowns. This hypothesis was not born out in the underpowered phase two resilience measure scores. Research continues into conceptualisation of these concepts and mechanisms of action (Battersby et al. 2010).

Further research with longer term outcome assessments built in is warranted to clearly identify what and how supported self-management can target unmet survivor needs.

Is supported self-management acceptable in outpatient cancer care settings?

The intervention was acceptable in hospital-based cancer clinical settings. Results from the survey measures completed by study participants and healthcare practitioners involved with recruitment for the phase two study indicated overall supported self-management program acceptability.

It is possible to infer from the data that some cancer survivors may prefer to do their own self-care; without support for self-management from healthcare practitioners (Pan et al. 2011; Omisakin and Ncama 2011; Kidd et al. 2008; Lawn and Battersby 2009). A key recommendation to address personal choice with regard to wellbeing practices is use of a screening tool. Cancer survivors can be screened for supported self-management program suitability (Waller et al. 2013). Cancer survivors screened as unsuitable for supported self-management intervention may be provided with alternative options. For example, watchful waiting can be offered to those who prefer self-care or who are currently self-managing effectively and not wanting additional support. Another potential option for those assessed with severe deficiencies in self-management ability may be referral to psychologist-delivered support services. Six psychology positions were funded in the 2014 Budget; with each of the six regional cancer centres in NZ allocated a psychologist (Ministry of Health 2014).

With regard to the intervention itself, the use of whakawhanaungatanga and other relationship building processes to establish therapeutic alliance was noted to be important for acceptability in the NZ setting (Dew et al. 2015; Walker et al. 2008; Slater et al. 2013). This was highlighted in the phase one data when one participant stated that qualification or ethnicity was less important to her than a caring approach. NZ research shows that the use of appropriate cultural processes is important for delivery of acceptable person-centred and culturally-centred care for Māori (Dew et al. 2015; Walker et al. 2008; Slater et al. 2013).

Effective communication between survivors and, health and supportive care workers was highly valued by study participants. The literature suggests that collaboration and shared

decision-making can contribute to decreasing the complexity of clinical care and increasing effective management of complexity associated with cancer (Battersby et al. 2010; Stiggelbout et al. 2012). Collaboration may also support treatment completion, regular follow-up attendance, and better management of psychosocial impacts. There is a role for supported self-management which has collaboration at the core of its foundation. Strategies utilised in supported self-management programs, such as goal setting and action planning, can help support collaboration and goal concordance.

The cancer survivorship framework of Klimmek & Wenzel (2012) categorised the often 'invisible' work of cancer survivorship. The acceptability-specific findings from the qualitative studies supported the concept of work. Cancer-related impacts were described. Some of these increased the workload and reduced the self-management capacity of those affected by cancer. It could be that the additional workload of self-management was beyond the capacity of some survivors to achieve. Tritter & Calnan, 2002a pointed out in their critique of the categorisation of cancer as a chronic condition, that supported self-management may not be realistic for survivors. However, the supported self-management tailored approach was considered acceptable by some focus group participants who stated they wanted to ensure that ongoing wellbeing support was available for others. Participants in the study were able to engage with the tools and care plan. What was lacking was sustained follow-up that would help support the survivor through the transitional survivor period and into extended survivorship. There was a need to assess capacity and consider whether goal-setting presented an unnecessary burden to survivors, as suggested by Tritter & Calnan (2002a). By increasing awareness of these areas of work, further nuanced discussions on interventions to support life and health complexity management for survivors can begin.

Intervention effectiveness is impacted by environmental context and these studies generate evidence that can be used to improve organisational policy and practice to make the setting more conducive for delivery of acceptable intervention. In the phase two study, study participants' responses to the acceptability survey provided data that support program acceptability. However, system-based study barriers presented a barrier to feasibility. A supportive system or environment can positively influence intervention uptake.

Can a supported self-management intervention program be feasibly integrated into the outpatient treatment setting?

Pilot projects embedding supported self-management approaches in cancer care have been carried out in Australia (Jefford et al. 2015) and the UK (Wilson 2008). There were no examples in the literature where supported self-management interventions had yet been fully integrated into the cancer care setting in NZ.

The basic pilot study design for this survivorship intervention study proved acceptable for delivery in cancer outpatient clinics. Modifications to the study protocol (Carroll et al. 2007; Horner, Rew, and Torres 2006) were necessary as the study progressed. The study processes provided insights into the burden and benefit of study participation within resource constraints (Beebe 2007) and helped the researcher gain experience delivering the intervention program with participants in the clinical setting (Beebe 2007).

Three specific areas of concern were identified as threats to feasibility in the study: referral pathways, survivor preparedness and outcome measures. Referral pathways hindered recruitment. It was noted that survivors' preparedness to engage in self-management intervention varied. The predominantly patient-reported outcome measures did not seem to assess program impact. This could mean that the program was ineffective or that the measures were inadequate. The known limitation of sample size was a key factor. These areas of concern will each be described in the following sub-sections.

The need for functioning and appropriate referral pathways

Study recruitment was problematic. Ethics committee requirements mandated clinician-guided referral of patients into the phase two feasibility study. Clinician-guided referral is considered an important way to protect patient vulnerability. In this study, the intervention delivery was proposed to take place in the clinic so that all colorectal cancer patients could equitably be offered the opportunity to participate. This was thought to reduce inequitable access which is the norm for survivorship programs (i.e. many programs are accessed via opt-in).

Focus group participants' consideration of supported self-management was reported to range from supportive to cautious acceptance. This indicated that brief presentation of study information to cancer patients during treatment in phase two was unlikely to achieve

enthusiastic participation by current patients. Nevertheless, there was no reasons indicated not to proceed and the phase two study progressed with assurances from clinical champions that recruitment would be viable. The biggest concern was recruitment of Māori participants and maximising Māori participation was a key aim of the study to meet identified needs and prioritise equity considerations in supported self-management intervention delivery (Signal et al. 2008).

In the end, recruitment processes were not delivered in the systematic way envisioned and recruitment was not as successful as hoped. Some individual clinicians described how they vetted potential study participants. The criteria used by recruiting clinicians was unclear. Anecdotally, one clinician described referring someone 'who could use some love'. In reality, there were few incentives for clinicians to present the study in the time-poor, disease-focused and complex environment of the cancer centre. Further, supported self-management was not a simple intervention to describe and often the time was not available for clinicians to explain it adequately. More time to offer better explanations regarding potential benefit to patients and clinicians might have increased enrolment rates (Berger, Neumark, and Chamberlain 2007). Further, participants who were approached could opt out and the likelihood that they did so was undoubtedly related, at least in part, to the way the study was presented to them. Therefore, the plan for equitable and systematic recruitment did not seemingly work out to be very equitable at all. A regular debrief with recruitment clinicians would be a valuable addition for future studies.

Multiple referral pathways worked better than a single pathway moderated. The importance of clinical champions working across referral pathways with multiple clinician referrers cannot be underestimated. Reliance on a single recruitment pathway presented a barrier to recruitment success in the phase two study. Clinician-based referral is impacted by factors including: clinical priorities taking precedent over study introduction, time pressures interfering with study presentation, and clinician leave putting a halt to recruitment. Goodwill was not enough to ensure study uptake and this aligns with results reported in another NZ-based study of The Flinders Program (Horsburgh et al. 2010).

The results from the pilot study indicated that colorectal cancer survivors can be recruited to participate in a supported self-management intervention study during treatment. Achievable procedures for recruitment were considered important to the study's internal validity (Prescott and Soeken 1989). There were enablers and barriers to recruitment identified. Main study enablers were clinical champions and participant incentives or koha.

A group of clinical champions enabled greater opportunity for patient entry into the referral pathway. The provision of monetary incentives for participants represented a recognition and contribution to the financial constraints associated with cancer treatment (Levit et al. 2013; Mehnert 2011; Hewitt, Greenfield, and Stoval 2006).

Key study barriers included timing issues and referral pathways that were not embedded well into clinical flow. Clinician-based referral pathways and recruitment procedures did not work well. Dilemmas related to timing and recruitment were not adequately resolved. This poses challenges for future studies. The implications of not addressing new approaches to intervention recruitment and timing mean high potential for study failure.

While evidence for supported self-management intervention is being developed, the need for accessible referral pathways is critical. Clinician-guided referral presented a barrier to patients equitably hearing about the study, although in theory, the concept of protecting patient vulnerability is sound. Alternative suggestions for future trial recruitment might involve enlisting clinical nurse-led recruitment, instead of oncologist or surgeon-dependent recruitment. It is hoped that, eventually, evidence-based interventions can be routinely embedded within redesigned cancer care pathways enabling efficient and equitable delivery of survivorship care. However, in the interim, committed and active clinical champions have been identified as crucial to intervention study success (Jefford et al. 2015).

Self-management terminology and preparedness

Survivors' values and priorities, as described in the phase one data, were identified to vary and change over time. The literature aligns with this description of a changing landscape and fluctuating levels of physical and psychosocial/spiritual impacts throughout the cancer trajectory (Dunn et al. 2013; Klimmek and Wenzel 2012; Jones et al. 2016; Egan et al. 2014). The literature and study results suggest tailored, flexible intervention content and delivery styles are needed that take into consideration variations in experience and priorities over time.

Phase one study participants found the terminology of self-management to be confusing and, by extension, off-putting to potential participants. The use of the term 'self' suggests that this intervention is not whānau-friendly. The importance Māori place on whānau for support, challenges the self-management terminology which identifies 'self' as singular.

Consideration of the Māori worldview and health philosophies, early on in this research, readily pointed to whānau inclusion. Supported self-management is best undertaken with whānau inclusion and this fits within this approach, despite the terminology. Secondly, management is not necessarily seen as an empowering term and may also be taken to mean 'going it alone'. This is not the intent of the intervention. In line with the recommendations by Jefford et al. (2015), survivorship terms that match those used by individuals and cultural groups are needed. A possible alternative terminology for survivorship intervention, such as 'moving forward', could be considered and is reflective of terminology that has been used in Australia (Jefford et al. 2015).

In terms of participant preparedness, some study participants seemed to be able to make the transition to survivorship discussions toward the end of treatment, while others were disengaged. This is congruent with findings from Jefford et al. (2015) that indicated variability in patients' readiness to engage with survivorship interventions.

Some of the issues identified in this study have been due to the need to adjust the supported self-management intervention approach developed within a chronic care population to a cancer population with unique perspectives and needs (Tritter and Calnan 2002). The Chronic Care Model was not originally developed to be applied in the cancer setting. The categorisation of cancer as a chronic condition is a relatively recent phenomenon due to epidemiologic shifts impacting on cancer survival. Application of chronic care approaches do not always have a seamless fit into the cancer setting and three ways that cancer disrupts this fit is described by Tritter and Calnan in their 2002 article. A disconnect between cancer and other chronic conditions prompts these authors to question whether supported self-management intervention is realistic for survivors. In response to this debate, the phase one results suggest that there is a gap in survivorship care that may be able to be addressed by this type of intervention. The phase two results indicate that this approach is potentially beneficial, but only for some people. Therefore, it seems that participation in a supported self-management intervention program is realistic but the extent of program utility needs further exploration.

Although Bandura (1977) identified self-efficacy as a key contributor to self-management competence, the phase one data in this study suggested that self-efficacy is not the only intermediary of effective cancer self-management. Other elements that were proposed as important by focus group participants were: 1) having someone caring, safe and knowledgeable to stand by you, and 2) clear clinical pathways for support. The focus

group findings indicated that the role of whānau, healthcare practitioners, society, and the health system also impacted on self-management competence. This reflects the concept that human behaviour is deeply embedded in, and shaped by, underlying social, economic, and legal-political structures (Golden and Earp 2012). Addressing unmet needs of cancer survivors is likely to require combinations of strategies, including supported self-management programs, aligned to environmental context and priorities.

Various factors can inform important priorities when considering embedding future intervention for survivors. More than individual motivation determines the success of intervention. The acknowledgement of the contribution of environmental influences, including the health system processes, is a critical aspect of the embedded model utilised. Participants in the focus groups described unmet needs. Comparable to the Australian focus group findings study by Jefford et al. (2008) survivors attributed feeling abandoned by health services to system-related barriers.

The need for effective outcome measures validated in the target population

There is a lack of consensus in the literature on which measures to use to effectively show the impact of supported self-management programs (Boger et al. 2013; Nolte and Osborne 2013). Many different measures have been utilised. The primary outcome measures used to evaluate supported self-management in this study were measures related to self-efficacy. These three measures were The Flinders Partners in Health scale (Petkov, Harvey, and Battersby 2010; Battersby et al. 2003), The Patient Activation Measure (Hibbard et al. 2004), and the Chronic Disease Self-Management Program self-efficacy scale (Lorig et al. 2001). Self-efficacy has been assessed with variety of validated self-report measurement tools. However, the underlying construct of self-efficacy is likely to be limited by lack of clarity around the conceptual relationship of the construct to the concept of self-management competence. One potential reason for this perceived lack of clarity may be related to the multi-pronged theoretical underpinnings of supported self-management which indicate potentially wide ranging outcomes. The intervention may not have included sufficient components that impacted on the patients' self-efficacy (e.g. verbal persuasion or role modelling). If that is the case, the role of therapeutic alliance, collaboration, therapeutic techniques and goal setting as components of the approach need further evaluation. On the other hand, these results could indicate that the outcome

measures for this construct were not adequate. However, it is worth pointing out again that the study was substantially underpowered to detect any improvement.

There was a lack of consistency shown in scores obtained from the three measures of self-management competence administered in the phase two study. For example, one person scored high on one measure of self-management competence and scored low on another. Concurrent validity was not achieved. The lack of obvious and consistent improvement across self-management competence measures might indicate differences between the measures underlying assessment constructs or that self-efficacy was variably impacted by the intervention. The validity and reliability of the measures recommended for use by Battersby et al. (2010) in their published Flinders Program protocol were found to have questionable use in the colorectal cancer-affected target population in these studies. This points to the need for further validation of recommended outcome measures within this population.

No significant or consistent intervention effect on proxy measures of self-management competence, distress, resilience, or QOL was found. However, since The Flinders Program pilot protocol was developed, the literature and research base has grown.

In 2008 Don Baken and colleagues at Massey University conducted a NZ-based study to validate the distress/wellbeing thermometer which was published in 2011. They found the distress thermometer to be acceptable for detecting broadly defined distress/wellbeing in NZ cancer survivors (Baken and Woolley 2011). They incorporated an impact thermometer into the measure to improve its psychometrics. In their study, distress/wellbeing thermometer and impact thermometer scores were added together. A cut-off score of 6-7 was indicated to have optimal sensitivity (0.86) and specificity (0.76) and the measure had adequate construct validity adequate test-retest reliability ($r=0.80$) when tested with a NZ cancer survivor cohort (Baken and Woolley 2011). Addition of the impact thermometer does not substantially increase the time to complete the measure. It would be recommended that any future NZ studies addressing self-management in cancer populations use this NZ-specific adapted version of the distress/wellbeing thermometer.

One of the aims of the pilot study was to explore and compare measures of self-management competence to recommend effective outcome indicators for future studies. Both short and longer-term outcome measures have been recommended for inclusion in pilot studies to allow for evaluation of sustained actions or behaviour changes (Carroll et al. 2007). The criteria for comparing outcome measures of self-management competence

in this pilot study focused on consideration of usability and acceptability at a pilot stage. This feasibility study did not focus on ascertaining intervention efficacy. Future studies are recommended to explore measure validity, reliability, sensitivity to change and symmetry with the intervention in further detail.

There is debate about the ability of any existing outcome measure to adequately reflect outcomes of interest in supportive care and survivorship studies (Gilbert et al. 2008; Naus et al. 2009; Tritter and Calnan 2002; Nolte and Osborne 2013). This is reflected in the predominance of qualitative methodologies reported in this context. As this literature broadens, more targeted quantitative work is needed to refine or develop traditional psychological measures or validate new quantitative measures as they relate to survivorship self-management. Recommendations on outcome measures to use for future survivorship self-management studies are made with extreme caution pending more research into this construct in the population.

It is important to assess the psychometric properties of outcome measures. It has been shown that the usability of instruments varies according to the target population (Boger et al. 2013). The reliability and validity of self-efficacy and other self-management support outcome measures in cancer populations has not been reported. More research is indicated to enable guidance on choice of the numerous potential proxy outcome measures to use to assess supported self-management competence in cancer-affected populations.

No clear conclusions could be drawn about the psychometric properties of the outcome measures utilised in this study. There are multiple measures of self-efficacy and all are likely to measure the complex underlying construct to some extent. The individual results varied between different measures suggesting that each is in fact measuring a different underlying construct. The data from the study cannot provide any indication which is the most valid in the context of a cancer population. It can only be concluded that The Partners in Health scale, the distress thermometer and the satisfaction/acceptability survey were the most easily administered outcome measures. The patient experience survey had low usability with it being a relatively long form (97 questions) and many took it home to complete and did not send it back. Alternate self-management-specific measures and measures to reflect intervention effectiveness need further investigation. It would be useful to get feedback from recruiting and intervention staff involved in future studies to ensure effective implementation.

Can supported self-management intervention in the hospital-setting address cancer care gaps reported by NZ cancer survivors?

Effective cancer survivorship interventions are needed in NZ. There have been growing calls for self-management research (Richardson et al. 2011; Sarfati, Koczwara, and Jackson 2016; Macmillan Research Unit 2009) but few studies to date have delivered evidence on supported self-management intervention in cancer-survivor populations. These studies raised a number of issues.

There continues to be a question about the ideal supported self-management intervention setting. The focus group participants and key informants expressed a variety of positions on this topic. Hospital-based intervention may reinforce dependency (Aziz 2007) and community-based opt-in intervention may get less buy-in (Beckmann et al. 2007). As this study took place in the hospital setting, adaptation of the program in that setting was seemingly indicated by the data.

The qualifications of the interventionist also elicited varied opinions. There were some people who felt interventionists should have healthcare practitioner qualifications while others felt experience and wairua were critical components of interventionist requirements.

The specific content of the intervention for cancer survivors was also unclear. The traditional focus of supported self-management is on supporting health promotion behaviours such as healthy eating and increasing appropriate exercise (van Weert et al. 2008; Gao and Yuan 2011; Anderson, Steele, and Coyle 2013). Within a cancer context, there are additional barriers to wellbeing that arise for survivors. These include fatigue management and dealing with fear of recurrence. These cancer survivor-specific issues may need to be specifically discussed during sessions to better target this intervention to the population. Although the intervention is based on patient preferences, needs and values, there is still a component of collaboration which relies on the expertise of a healthcare practitioner to raise issues in conversations about potential impacts.

In both the intervention and control groups, the pilot study outcomes data were inconsistent. Some participants improved, while others appeared to do worse, and others showed no discernible impact based on outcome measure scores. Again, these results are likely due to chance due to low participant numbers. However, there is the theoretical

possibility that the poor follow-up results for some participants reflects unintended consequences of the intervention.

The patient experience measure results are particularly puzzling. The intervention group rated the aspects of care considered strengths by the 2009 administration respondents lower than both the baseline group and the phase two study control group. This could reflect the impact of raising awareness of the potential for cancer care to improve. This observation aligns with the overall better scores given by the intervention group respondents around the aspects of care that reflect non-clinical provider dependent opportunities for improvement. These may have been addressed by the intervention increasing the ratings of patient experience in these perceived gap areas.

However, it must be remembered that the literature alludes to differential effects for those participating in supported self-management programs (Salvatore et al. 2015; Newbould, Taylor, and Bury 2006; S. Lawn et al. 2007; Wilson 2008). This was an underpowered feasibility study so the results from outcome measures are only indicative. Nevertheless, there are suggestions of potential impact on important outcomes associated with wellbeing from the data and these are promising in light of equity considerations (Greenhalgh et al. 2011) and potential for improved follow-up care (Jackson 2016). Supported self-management is one approach to addressing cancer care gaps reported by NZ cancer survivors. It is not a one size fits all. Further research into the utility and effectiveness of this type of intervention is indicated. A natural progression of this work would be to determine whether some groups benefit more from this intervention, than others, to further address equity considerations in light of the literature that indicates this approach is less effective for ethnic minority groups (Greenhalgh et al. 2011).

Even though the 'standard supportive care' control arm of the study proved to be feasible, ethical questions were raised by study advisors and the ethics committee about withholding the potential benefits of the intervention. In NZ, usual care generally does not entail standardised support for self-management during and after treatment. In future studies, if the efficacy of the intervention is established, it is recommended that different intervention session structures or modes of delivery of the intervention be tested using a pre- and post-test design without randomisation to a control group.

Evaluating the research frameworks

The evidence derived from any study is a product of the study framework. The MRC guidance on complex interventions provided the basis for a phased approach to the design of these studies (Craig et al. 2008). This frame and stepped approach guided iterative development and evaluation of intervention evidence to inform effective delivery in healthcare environments. Often full-scale intervention studies are embedded into the environment without adequate consideration of multi-level impacts on intervention success. This increases the potential for research study failure at potentially great cost to the public and the fields of study under research. The use of a framework aims to stack the odds against intervention failure by incorporating preliminary work to identify enablers and barriers prior to full-scale intervention delivery.

The author's interpretation of the MRC guidance on complex intervention, called for methodical build-up of evidence through qualitative modelling and a randomised pilot study. These specific approaches were not pre-determined by the guidance. The guidance allows for flexibility in approach toward evidence development. This is in line with recommendations from the Cochrane Collaboration (The Cochrane Collaboration 2008). The Cochrane Collaboration advises that there is no 'gold-standard' intervention study design in fields outside of biomedicine (The Cochrane Collaboration 2008). Therefore, the types of studies or approaches to development of evidence are able to be guided and matched to the intervention goals and environment.

Reflections on overall study design

There were key priorities considered that impacted on the study design. The first priority was to respect and apply best-practice principles for research involving Māori (Health Research Council of New Zealand 2010; National Ethics Advisory Committee 2012). The phase one study sought to include an indigenous perspective. The phase two study was transformative in that the research itself addressed some unmet needs, contributed to increased awareness of survivorship, and informed potential for change in care pathways.

The studies that developed evidence for the intervention approach were delivered using sequential mixed methods. The qualitative and quantitative methods utilised were considered complementary and sequential; neither was considered dominant (Mertens et al. 2010) and triangulation was not the goal (Strauss and Corbin 2008).

The qualitative enquiries provided interesting and useful insights into survivors' cancer experiences and self-management. The data indicated unmet needs and provided insights into the perceived utility of a supported self-management intervention program in cancer care settings. Qualitative data was collected from two focus groups: a Māori only group and a mixed ethnicity group. These rich data sources were supplemented by interview data collected from healthcare practitioners.

The quantitative exploratory pilot study design provided an opportunity to better understand the links between intervention, outcome measures, data collection processes and analyses. It was hoped that the study design would meet the objectives and also yield insights into the numbers of potential participants required to obtain adequate power levels for future studies. However, due to low recruitment, this did not occur. It may be useful to conduct a further feasibility study with a revised protocol to better indicate potential recruitment numbers.

The phase two study was a feasibility study. Modifications to the protocol indicated during the study were extensive. Issues with the phase two study design were identified in three main areas: referral pathways for recruitment, patient's intervention readiness, and outcome measures. The proposed recruitment pathways were hindered by lack of referrals to the study. Once a patient was recruited, patient suitability and interest was found to be variable indicating a need to explore pre-screening for vulnerability and intervention readiness. The assessments were readily and easily administered with consenting participants but the ability of the chosen measures to reflect intervention outcomes was deemed questionable. The pre-post assessment design was inadequate to assess outcomes. Timing for delivery of the single short-term follow-up assessment was problematic. Follow-up assessment timing coinciding with the six-week follow-up appointment at the hospital was inadequate. Research shows that transitional survivorship is a time of particular difficulty for survivors and is associated with the need to manage multi-level anxieties, decrease attachment to specialist care providers and re-establish life routines (Hewitt, Greenfield, and Stoval 2006; Zapka et al. 2012). This could have impacted on outcomes measured. Longer-term follow-up is recommended.

The literature addresses the question of research design for these types of studies. Some authors question the validity of the need to generate high-quality RCT evidence for quality of life interventions (Petticrew, Chalabi, and Jones 2011). Some NZ psychology researchers have advocated for alternative approaches to intervention research studies,

taking into consideration alignment of research goals with survivors' therapeutic goals in real world settings or, alternatively, with the organisations' health policy and cost-neutral goals (Heron 2009; Croy 2010). If evidence-based survivorship research is to progress, an understanding and case for alternative research designs may be helpful. Alternative designs might include quasi-experimental studies that do not use random assignment. This would enable the intervention to be delivered to those assessed to be at risk of poorer outcome. Risk stratification is likely to be a component of any future support intervention considering that resources are limited (Central Cancer Network 2016).

Reflections on the analytical frameworks

Framework Analysis was used for the evaluation of the phase one qualitative data. Pragmatically, framework analyses helped focus the extrapolation of data in order to meet the objectives of the study. Data were first condensed into themes. The themes were framed by the Te Whare Tapa Wha (Durie 1994) four cornerstones of health and well-being: physical, emotional, spiritual and social. Data were analysed deductively according to what fit into the frame. An emphasis on deductive analysis was undertaken in this study to streamline the presentation of results and reduce complexity in data interpretation. Anomalies in the data were found that did not fit cleanly within the chosen frame but these were not thoroughly reviewed. The interpretation of the results would benefit from a complementary inductive analysis to more comprehensively review this data. This approach may reveal other issues around self-management in a NZ context for survivor populations.

The RE-AIM framework was used for the evaluation of the phase two quantitative data. The use of the RE-AIM framework required interpretation but it was ultimately found to be usable and suitable for reflecting the feasibility study outcomes.

Study strengths and limitations

Key study strengths

These two studies had important strengths. This research aimed to be relevant for Māori. The incorporation of a Maori-specific focus group in the phase one study was intended to

promote cultural understanding and cultural safety in intervention research. This may inform future studies that can improve equity in cancer care for Māori.

This is the first survivorship study which was situated in the acute cancer setting within hospital clinics. Survivors who participated were motivated to share their experiences in hopes that these could contribute to improvements in care for future cancer survivors. This project brought a greater degree of survivorship awareness into the clinical environment. Clinical champions have been critical to study success. Multiple clinical barriers were identified and addressed in order to embed the intervention into clinical flow. This clinician support shows awareness of the issues and an interest in putting in place better processes to address survivorship issues.

The MRC complex intervention framework guided the design and enabled the NZ participants' experiences and described impacts to guide pilot study design. While pilot studies enable useful consideration of the acceptability and feasibility of intervention processes and delivery, they also can contribute to improving the scientific integrity of future RCTs (Thabane et al. 2010). A key strength of these studies is the use of the MRC framework which has provided a strong template, foundation and learnings to inform future programs of interventional research.

The engagement with study advisors was also considered a key strength across both studies. These relationships enabled wide consultation on the potential meaning and emphasis placed on specific study results. Multiple advisors were engaged and they included international intervention experts and local cultural, clinical and research experts.

The author was involved in all focus groups and key informant interviews. Therefore, when it was time to analyse the transcripts, the words and their associated context and meanings, were able to be reviewed as the author experienced them. The emerging themes were also able to be better described to study supervisors and advisors that checked them. This informed the interpretive approach that was consistently applied across all group discussions and key informant conversations. Although the phase one data on survivors' experiences may not be generalisable to the wider NZ survivorship and health practitioner communities, it does show that cancer impacts are often felt long after treatment ends for many. This finding aligns to the first recommendation of *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt, Greenfield, and Stoval 2006) that calls for raising awareness of these issues.

The phase two study used a robust RCT design. However, the protocol needed modification during the study. It would have been problematic to continue with a design that was not working to ensure fidelity. The basic study design enabled a useful 'dummy run' of processes and procedures for future studies. This type of pilot work provided an important, but often neglected, step toward development of an acceptable and feasible protocol for larger intervention studies.

Another strength was that the study achieved a range of participants by gender, ethnicity and age. All participants completed multiple validated outcome measures that might be useful for inclusion or exclusion in future studies.

Key study limitations

The two studies had several limitations. The limitations have been named in relation to the qualitative phase one and quantitative phase two studies separately. For both studies, the size of the participant groups was a key limiting factor. The majority of participants across both studies were colorectal cancer survivors. This limited the opportunity for other interested cancer survivors to share their experiences and views. It also limited the generalisability of the results to other cancer survivors. It is important to point out that it is not clear who chose not to participate in the studies. It is not known if the studies participants comprised the proposed subset of survivors that would suit a supported self-management program intervention. Selection bias impacted on both studies. Adequate procedures for obtaining information on people who chose not to participate are important to refine for future studies.

In phase one, there were important limitations to consider. This information builds on the limitations described in Chapter four. First, the foundations for delivery of the study could have been enhanced through stronger identified linkages between Klimmek and Wenzel's (2012) survivorship framework and the discussion guides. Second, data collection could have been improved given more time. The time constraint for focus groups and interviews limited data gathered. This especially impacted on the large multicultural focus group and may have prevented some people from being heard. In hindsight, it may have been better to split the large focus group into two smaller groups but, at the time, it was thought better to go ahead with a group of 18. Part of the reasoning was that some focus group members brought whānau and it seemed better to keep the group together. In NZ, flexibility around focus group management is required due to the unknowns of who will actually show up.

For example, sometimes a focus group turns into a hui or fono, meaning a large gathering. Different techniques for engaging with larger groups are needed. In this case, the large focus group was managed as a focus group but with both individual and group work time for participants to address questions. Responses seemed frank and everyone contributed.

In the phase two study, limited recruitment prevented the study from achieving a minimum of 30 participants per arm in the pilot, as suggested by guidance from one study (Lancaster, Dodd, and Williamson 2004). Further, non-standard selection processes were used to recruit the 27 participants. The small sample size increases the risk of sampling error (Balnaves and Caputi 2001). It is difficult to know what, if any, impact this would have on study results. It is possible that the study may have achieved greater insights from a larger pool of participants and equitable access to study participation. The key external validity issue arising from these studies is likely related to representativeness of the data.

In phase two, as previously stated, by far the biggest threat to internal validity was small sample size. In addition, research assistants carried out the follow-up assessments for the intervention group participants, but they were not blinded to the randomisation assignment as would have been best practice. Participants were also not blinded to whether they were in the intervention or control arm of the study. OF course, this is not possible in this type of intervention pilot. This information bias may have impacted on the results. For example, those who underwent the intervention may have felt a stronger desire to report positive findings to support the researcher which would exaggerate any positive effects of the intervention. On the other hand, the potential for research bias was minimised by use of standard assessment instruments that could have counteracted, in part, some information bias. The extent that information and researcher biases contributed to the data were not able to be assessed but were important to recognise.

There was a limitation introduced due to the tension between tailoring and fidelity which occurred in the phase two study. Fidelity is related to reproducibility of the intervention. Due to the personalised or tailored nature of supported self-management approaches, there is no single measurable dose. There are sessions. Behavioural interventions cannot easily be measured as a standardised dose. The same intervention is not able to be carried out in the same way with everyone. The issue here is that there is a tension between delivering an individualised programs which differs between people on one hand, and treating the intervention as if it is a single 'standard' intervention. Tailored interventions are person-centred and individualised. They are considered more efficacious

than single component symptom-centred interventions. Wellings et al. (2006) in a review of health behaviour studies in 59 countries, concluded “Evidence from behavioural interventions shows that no general approach...will work everywhere and no single component intervention is likely to work anywhere” (1724). There is, therefore, a definite need indicated for tailored interventions. In NZ and overseas, behavioural interventions have been shown to improve psychosocial health for individuals in the short term (Jacobsen, Holland, and Steensma 2012; National Comprehensive Cancer Network, Holland, and Bultz 2007; Levit et al. 2013; Croy 2010). However, when compared to biomedical studies, it is easy to be critical of the results based on fidelity concerns.

Also, there was some potential for contamination noted between participants in the intervention group and the control group. Participants may have discussed the intervention while waiting for or receiving their treatments.

Intervention setting, delivery and content impacted on intervention outcomes. The setting was the hospital but that may have not been the best setting for supporting self-management in context of everyday life. It is also important to recognise that there was only one interventionist, the author. Therefore, intervention effectiveness depended on just one individual. There was no Māori interventionist. The interventionist would have had an impact on intervention delivery, cultural relevance and results. The intervention content also needs evidence for what is required in cancer survivor populations.

Feasibility issues characterised both the phase one and phase two studies. Results from these small studies should not be considered out of context. This pilot generated preliminary data that allowed for ascertaining survivor experiences, testing and adaptation of an intervention protocol, usability of forms and content, and testing of instruments for measuring outcomes. The mixed methods feasibility study yielded valuable information to inform future studies. The internal and external validity issues identified will inform future study designs.

In the phase two, a large degree of deviation was required from the protocol due more to recruitment-related barriers than intervention delivery barriers. Protocol redesign was required throughout the study implementation time frame. As a feasibility study, modifications were allowed in the hopes of informing a more robust future study protocol. Although fidelity was compromised and outcomes impacted, lessons learned and modifications applied to the protocol may be useful when future studies are considered.

Implications

Implications for practice

Documenting the experiences and views of cancer survivors enables awareness to be raised of the impact of cancer survivorship. The experiences of survivors reported in this study indicate that there is a gap in survivorship care and support for a redesign of cancer care pathways to incorporate a focus on addressing survivorship impacts. There are significant physical and social, emotional and spiritual needs going unrecognised and unaddressed. Cancer-related impacts contribute to life complexity and vulnerability over the long-term for survivors.

Survivorship impacts for Māori are multi-faceted. The work of cancer survivorship needs to be further explored for Māori and the framework of Klimmek & Wenzel (2012) expanded upon to show how it applies for this and other indigenous groups.

A person-centred intervention can be guided by existing frameworks. Te Whare Tapa Wha (Durie 1994) and The Chronic Care Model (Wagner et al. 1996) provided useful foundational and logical frameworks for progressing research into supported self-management program intervention in cancer care settings. Further research applying the cancer survivorship framework of Klimmek & Wenzel (2012) would help build knowledge around cancer survivorship for Māori and non-Māori in NZ.

Implications for research

There is considerable concern amongst practitioners in the fields of psycho-oncology, supportive care and survivorship that research has failed to show efficacy of therapeutic and interventional approaches (Dow 2003; Grunfeld et al. 2011; Viswanathan et al. 2014; Richardson et al. 2011). There is practice-based conviction among practitioners that the interventions and approaches utilised within these disciplines make a difference but this has not been consistently validated through evidence-based research. The assumptions from these studies that show little or no impact is that the interventions studied were ineffective. This may be so but, there are two alternative explanations or contributing factors. One is that the outcome measures utilised to assess complex human behaviour may not be as robust as they could be. The second contributing factor being that the

outcomes identified are not those that are expected or being measured, so may go unrecognised.

The patient-reported outcome measures, albeit underpowered and only reflective of short-term outcomes in the phase two study, did not indicate clear utility for this program. There is a need for a systematic review of international research on outcome measures used in survivorship studies, including cancer self-management studies. Research is needed to explore how the measures identified align with the hypothetical mechanisms of action associated with supported self-management. According to Battersby et al., self-management is a difficult concept to operationalize (Battersby et al. 2010). Therefore, it is understandable that there is a lack of consensus on valid cancer self-management competence measures. However, the use of outcome measures with questionable validity in cancer populations, limits the ability to build the evidence base for survivorship and self-management interventions.

Recommendations

Practice recommendations

This research contributes to increasing the awareness of the impacts of cancer survivorship and provides pilot intervention data to help inform ways to address survivors' unmet needs. The first recommendation from the IOM report on cancer survivorship is to raise awareness of the broad and holistic needs of cancer survivors (Hewitt, Greenfield, and Stoval 2006). Although numerous papers have been published overseas on the needs of cancer survivors (Earle and Neville 2004; Cooley 2010; van Mossel et al. 2012; Faller et al. 2016; Eiser 2007), the importance of local context is critical for convincing policymakers of the need for interventions to address overall wellbeing for Māori and non-Māori cancer survivors in NZ. The evidence-based research platform enhanced by these studies presented in this thesis can be the springboard to raise awareness of unmet cancer survivor needs in NZ.

I have argued that ensuring appropriate systems, services and support for cancer survivors is a priority area for public health research and in NZ healthcare practice. Assessment of distress/wellbeing and unmet survivor needs is not enough. Interventions to address unmet needs, suited to the unique NZ environment, are needed. This study contributes to the evidence base but no definitive practice recommendations can be made now regarding this kind of intervention.

Although there are many potential survivorship interventions that could be studied in the NZ context, a supported self-management program was chosen for further study because it was indicated by classifying cancer as a chronic condition. The data did not answer whether this classification was suitable or helpful. Supported self-management is not considered to be a replacement for other interventions but is a tool to enable more standardised and appropriate access into these services that support moving forward after cancer treatment.

Supported self-management was not proposed as a stand-alone intervention to meet the needs of all cancer survivors. It was not seen as a replacement for specialised psycho-oncology or other high intensity and specific interventions targeted to complex needs. However, it was an approach that could be carried out in the hospital setting to address survivorship care. It aimed to support survivors and caregivers to move forward during

treatment. It utilised a screening tool and enabled development of a care plan that was based on survivors identified preferences, needs and values. It could be used as a stand-alone intervention for those with high-levels of self-management affinity and could assess suitability for referral to other services for those who wanted to increase their self-management competence in ways agreed to be acceptable.

Possible survivorship pathways are shown in Figure 22. Because it is unlikely that there will be a single survivorship pathway acceptable for all survivors, future work must use risk stratification and individual preferences, among other indicators, to inform collaboration between health and supportive care workers, and survivors on moving forward. Moving forward is made easier if options are made available and if discussions are initiated before the end of treatment and reviewed at follow-ups.

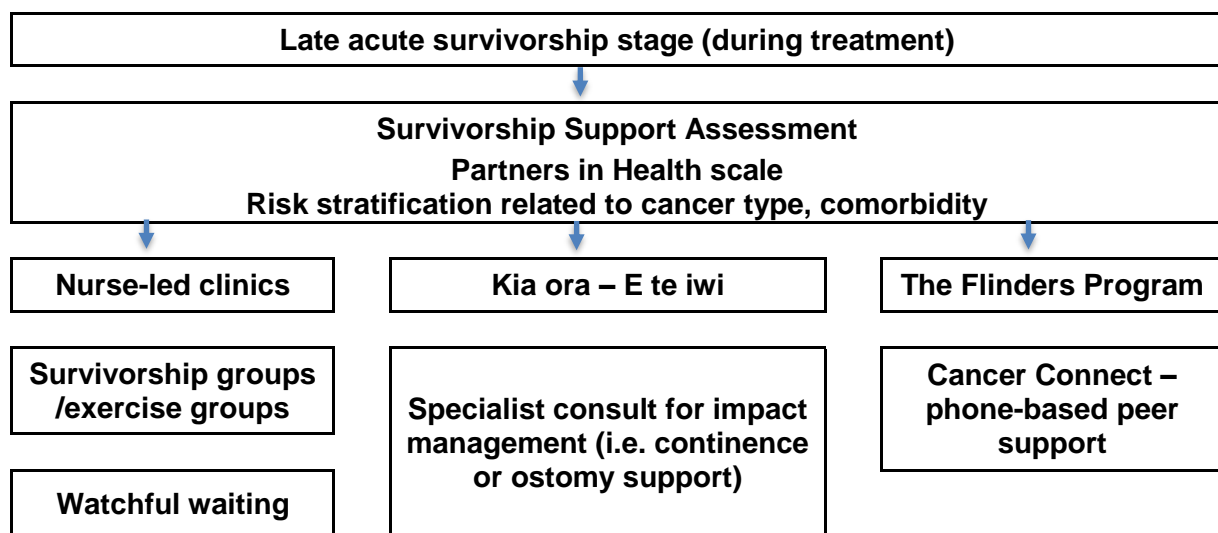


Figure 22: A selection of survivorship care pathways

Key practice recommendations to improve survivorship intervention delivery and outcome assessment include: more research into intervention timing to coincide with survivor readiness, delivering interventions within brief timeframes, and working within variable appointment timeframes that were adaptable based on changing appointments. It was not possible or desirable to deliver this intervention to all cancer survivors, so assessing readiness and conducting risk stratification based on needs could help target supported self-management interventions for those who may benefit the most.

Research recommendations

These studies sequentially delivered phases one and two of the MRC framework on complex interventions. The data from these studies contributes to the literature. On balance, more research is warranted and progression to a phase three trial is recommended with reservation. Prior to progressing another study, the data from these studies suggest there is a need to re-assess intervention terminology, appropriate settings, interventionist requirements and intervention content targeted for cancer survivors. Further, a screening tool to assess preparedness for self-management is needed.

Survivorship terminology is problematic in the NZ setting. Further debate is encouraged to identify terms acceptable to key stakeholders. Terminology confusion should not stall progress toward developing evidence for survivorship interventions.

With regard to settings for the intervention, future survivorship studies would work best if they could bridge between treatment times and the post-treatment transition period. For example, if at least two post-treatment rehabilitation assessment sessions took place during treatment appointments, further sessions could take place after the final treatment appointment. Transition from clinic-based survivorship to community-based survivorship could then take place more seamlessly. Community-based survivorship interventions might include counselling support for biographical work, support groups or further supported self-management delivered in primary care.

Adequate recruitment and assessment processes are critical to intervention success. Recruitment could be enabled by appropriate intervention staff identifying eligible participants through clinical record review of patients with upcoming appointments. A research assistant could speak with the healthcare practitioners, get approval, and approach potential participants during their clinic appointment. With regard to assessment, it is recommended that readiness to engage with survivorship care be assessed during treatment, at the final treatment appointment, and at post-treatment follow-up.

The Partners in Health scale was the screening tool that was developed for The Flinders Program. It is an integral component of the program. The Partners in Health scale is only one measure of self-management competence available. Further research to validate alternative self-management competence measures in cancer affected populations is needed. Further research could address the mechanisms of action for the approach and

help determine what a reasonable size change in score would be associated with clinical significance.

Research shows that most survivors who were working when they received their diagnosis, return to work (Mehnert 2011). Vocational support is indicated. Therefore, equitable survivorship intervention may need to be delivered both during treatment for some, and outside treatment settings and work hours for others.

Clinical champions can support the work and have been identified as critical for future research (Jefford et al. 2015). Clinical champions can support colleagues to comply with study protocols.

Further research and future survivorship care pathways would also benefit from:

- Inclusion of whānau included through an integrated Whānau Ora approach with content that incorporates cultural processes as desired;
- Motivated, skilled and accredited interventionists who are caring and motivated to deliver person-centred and tailored interventions;
- Incorporation of longer-term outcome measures, at 6 or 12-months post-treatment, and inclusion of 'harder' process or clinical outcome measures to more effectively show efficacy and utility of the intervention in the clinical and policy environments;
- Redesigned systems (e.g. redesigned care pathways) and adequate funding models in place at both the organisational and national level to support survivorship initiatives and resulting change in practice or processes;
- More studies, including those that incorporate cost/benefit analysis, to increase the evidence base for survivorship.

Future research should focus on trialling and evaluating a range of new initiatives in different areas to further fill the gap in cancer survivorship care and delivery. If a multi-site supported self-management RCT is progressed based on these recommendations, a scaling up strategy would need to be included to help address sustainability concerns related to the intensity of resources and labour required for intervention maintenance in various hospital settings. If barriers related to study processes and outcome measures can be addressed, further research is warranted.

Conclusions

The findings from this research make several contributions to the current literature. These studies raise awareness of the growing issues and impacts associated with cancer survivorship in NZ. This is the first NZ-based study of supported self-management intervention carried out with a cancer-affected cohort. The data show that cancer has impacts on NZ survivors. Health and supportive care workers want to provide better support.

The identified themes from the phase one study have been placed in the context of the wider literature. The study has identified many points of synergy, but some differences noted in how cancer survivorship impacts are experienced and described differentially between Māori and non-Māori. These findings suggest that tailored intervention approaches, that can accommodate individual and whānau differences in emphasis and priority values, are indicated for further research.

This is the first study to link cancer survivorship to The Chronic Care Model (Wagner et al. 1996) as the foundation for supported self-management intervention delivery within a cancer care environment. The findings add to the international literature by highlighting enablers and barriers to embedding survivorship intervention in cancer care settings. This research also adds to the research supporting improvements in quality colorectal cancer care in NZ.

Interventions to address cancer care gaps for survivors need to be tailored, easily accessible and flexible for patients. Equally, they should be supported by robust systems for equitable delivery and evaluation. In these studies, supported self-management was explored as a way to support survivors in active treatment and as they transition to post-treatment survivorship. Supported self-management intervention programs emphasise partnership and collaboration with experts to build individual knowledge, attitude and strategies. The Flinders Program was delivered as a tailored intervention that incorporated other interventions to address survivors' priorities, values and goals.

The Flinders Program is a good option because it has flexibility to be culturally relevant. While there were challenges with the pilot study, and the evidence could be interpreted as equivocal, it seemed to be an acceptable and somewhat feasible option. The next logical step, as indicated by the MRC framework, would be progression to a phase three multi-site clinical trial.

In light of The Chronic Care Model (Wagner et al. 1996), there are still questions concerning the fit of this model to cancer survivorship and its accompanying complexity. Delivery of The Flinders Program in the cancer care setting did not adequately address the broader inherent structural factors and risks that impact on the intervention. However, by pointing this out, it is hoped that this research will prove useful for broadening the perception of intervention as only one facet of a complex system of influence aimed at improving health status and outcomes.

The acceptability of The Flinders Program was indicated for NZ populations. Although the approach is acceptable, integrating survivorship intervention to improve the quality of cancer care in the clinical environment faces many challenges to feasibility. Results of the studies reported herein, based on small numbers of participants, did not clearly show utility of the intervention. Future studies should concentrate on how to best pre-screen survivors for preparedness to undertake supported self-management. This can help reduce potential unintended consequences and threats to fragile coping mechanisms. The following environmental factors that impact on intervention delivery require further work: functioning referral pathways for study recruitment, pre-screening processes for intervention readiness, and stratified intervention delivery mechanisms. Another fruitful area for further work would be to investigate development or identification of robust outcome measures relevant to chronic care and validate them with cancer survivors.

The objectives for the phase one and phase two studies were achieved. Both studies presented in this thesis provide evidence on the acceptability, feasibility and early utility of supported self-management in cancer care. This data contributes to the small pool of cancer survivorship studies. It is one of only a handful of studies to prioritise intervention equity. Supported self-management intervention or other tailored approaches to address survivorship impacts are indicated for further study.

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APPENDICES

Appendix A: A summary of 18 colorectal cancer experience studies described as self-management studies

Study	Phase of illness trajectory	Sample and setting	Self-management intervention studied	Key findings
Galloway & Graydon, 1996	Treatment	20 men & 20 women with colon resection in one Canadian hospital interviewed pre- and post-discharge	None	<p>Individuals post-surgery for colorectal cancer have low levels of symptom distress, moderate uncertainty, and have a greater need for discharge health information as perceived uncertainty increased.</p> <p>The authors' findings support Lazarus & Folkman's Transactional Model that people seek information to cope with uncertainty that may lead to stress if the stressor overwhelms perceived coping ability (Lazarus and Folkman 1984).</p> <p>"Uncertainty may be increased if symptoms are unexpected or do not form a distinguishable pattern" (p. 112).</p> <p>The unexpected long-term duration of side-effects in people post-treatment leads to colorectal cancer survivorship uncertainty and stress.</p>
van Mossel et al., 2012	Across the continuum	Narrative scoping review	None	<p>People affected by colorectal cancer are rarely asked about their info needs in published research, but, on the other hand, they cannot be expected to know/anticipate what info they will need or find useful, nor when.</p> <p>Practical advice related to diet/nutrition or bowel management not often reported/researched.</p>
Pan et al., 2011	Treatment	35 cancer patients in one Taiwanese hospital interviewed at 1 week and 1,2 and 3 months after surgery	None	<p>Frequency of using self-care strategies did not change over time, but the self-care strategies used changed.</p> <p>Dietary modification and exercise highly rated self-care strategies.</p> <p>Factors affecting self-care strategies were age, cancer stage, defecation frequency and diarrhoeal distress.</p>

Study	Phase of illness trajectory	Sample and setting	Self-management intervention studied	Key findings
Pan & Tsai, 2012	Treatment	35 cancer patients in one Taiwanese hospital interviewed at 1 week and 1,2 and 3 months after surgery	None	<p>Quality of life (QOL) changes and generally improves for physical health satisfaction and environmental relationship satisfaction from 1 week to 3-months post-surgery.</p> <p>Mental health satisfaction of patients with L hemicolectomy is higher than patients with R hemicolectomy.</p> <p>Satisfaction with mental health is lowest overall and does not improve with time.</p> <p>Low QOL associated with people who are younger, women, have had R hemicolectomy and experience higher diarrhoea distress.</p>
Ohlsson-Nevo et al., 2012	Post-treatment survivorship	13 patients & 13 partners interviewed separately one year after colorectal cancer surgery	None	<p>Qualitative descriptive interview study</p> <p>Main theme 'Life is back to normal and yet not'</p> <p>'Life has a shadow of death' 'The treated body sets the rules' 'To share or not share the illness'</p> <p>Views differed within and between couples which makes it difficult to meet the needs of both patients and partners during treatment and recovery.</p> <p>Main influences on lives were uncertainty and condition of the patient. Support, coping styles and info needs differ within whānau.</p>
Chao et al. 2010	Treatment	110 colorectal cancer patients from one Taiwanese hospital	None	<p>Study examined factors associated with the perception of acceptance of disability.</p> <p>Poorer acceptance of disability associated with shorter disease duration, stoma, lower education level, or higher cancer stage.</p>

Study	Phase of illness trajectory	Sample and setting	Self-management intervention studied	Key findings
				Other studies (breast cancer specific) have indicated that a useful intervention is one that "...focuses on helping patients accept their disease, and then learn how to live with cancer and its various ramifications..." (2279).
Beaver et al. 2010	Post-treatment survivorship	27 patients from one hospital trust in England	None	Qualitative descriptive interview study Main theme 'knowing what to expect' 'living with altered bowel function' 'trial and error' 'information and support from specialist nurses' Perception of being left to cope alone at home
Kidd et al. 2009	Treatment	11 patients from one Scottish cancer centre before and after 6-months chemotherapy treatment	None	Qualitative descriptive longitudinal interview study Study explored self-care experiences and views on perceived control in managing treatment related side-effects. Interventions should focus on enhancing patients' perceived control over managing side-effects. People may be 'high' or 'low' perceived controllers. High perceived controllers more likely to self-care and less likely to rely on others to manage. Low perceived controllers less likely to self-care and more likely to rely on others to manage side-effects.
Baravelli et al. 2009	Survivorship	20 survivors and 100+ healthcare professionals participated in this Melbourne, Australia based study	None	Two studies – one of survivors and their primary care practitioners; the other a survey of nurses and medical practitioners All participating survivors and primary care practitioners interviewed as Part of Study 1 reported the Survivorship Care Plan as useful and relevant.

Study	Phase of illness trajectory	Sample and setting	Self-management intervention studied	Key findings
				<p>The survivors commented most positively on the incorporation of the 'novel' practical components included regarding lifestyle and psychosocial care.</p> <p>"It seems that the healthcare practitioners are most comfortable reporting 'just the facts' and are not sure about providing lifestyle and psychosocial care advice or info about recovery from potential toxicities and self-management."</p>
Paddison et al. 2009	Treatment (surgery)	51 patients from one hospital in Auckland, New Zealand assessed for fatigue at 6 time points	None	<p>Study of expectations and realities of post-surgical fatigue assessed at baseline and 2, 5, 14, 30 and 60 days post colorectal cancer surgery.</p> <p>Findings suggest that most aspects of fatigue resolve within 1-2 months of colorectal cancer surgery.</p> <p>However, study shows feelings of fatigue and impacts of fatigue resolve across significantly different time frames.</p> <p>Preoperative expectations are associated with the resolution of post-surgical fatigue with minimised expectations was associated with an increased likelihood of experiencing post-surgical fatigue that was significantly more sustained than reported by patients with more realistic expectations.</p>
Hawkes et al. 2009	Treatment	RCT – 350 total participants in Queensland, Australia	Tele-based lifestyle intervention – up to 11 sessions delivered over a 6-month period	<p>Protocol for a two-armed prospective RCT</p> <p>Evidence-based intervention approach with strategies drawn from the core components of Acceptance and Commitment Therapy (ACT).</p> <p>ACT strategies used to enhance positive lifestyle behaviours not as a psychotherapeutic intervention.</p> <p>"Previous research has suggested that interventions to improve quality of life after colorectal cancer may be most effective if they target symptom management,</p>

Study	Phase of illness trajectory	Sample and setting	Self-management intervention studied	Key findings
				<p>psychosocial and lifestyle variables, or health behaviours, in a comprehensive and integrated approach". Steginga et al, 2009</p> <p>"The health coaching sessions will be delivered by study trained health coaches who will be guided by a custom developed web-based computer application and will key enter all session information"</p>
Molassiotis et al. 2009	Treatment	164 patients from one hospital in England with colorectal or breast cancer receiving oral capecitabine	Home care program vs standard supportive care	<p>Physical symptom focused study outcomes included toxicity levels, anxiety, depression, QOL, service utilisation.</p> <p>A symptom-focused program works best during the initial two cycles of chemotherapy to improve treatment and symptom experiences.</p>
Kidd et al. 2008	Treatment	11 patients from one Scottish cancer centre before and after 6-months chemotherapy treatment	None	<p>Qualitative descriptive longitudinal interview study</p> <p>Study explored self-care experiences and views on perceived control in managing treatment related side-effects.</p> <p>'Self-care was not simply a process of physical management, but was also about an emotional process of transition in which they employed strategies to create order, reconstruct their sense of self and maintain a sense of normality" (475)</p> <p>"Self-care for patients undergoing treatment for cancer is largely carried out in a quest to preserve self-identity and maintain normality and to manage the physical and emotional impact associated with treatment."</p> <p>Preservation of identity is a key role of self-care</p>
Nikoletti et al. 2008	Survivorship	101 patients from one hospital who	None	Retrospective, descriptive survey

Study	Phase of illness trajectory	Sample and setting	Self-management intervention studied	Key findings
		underwent colorectal surgery in the last 6-24 months		70% had a change in bowel habits after surgery Information needs reported were diet, managing change in bowel habits and pain, and ongoing concerns about managing symptoms.
Siassi et al. 2008	Treatment	35 patients from one hospital in Germany with a stoma after colorectal cancer surgery surveyed at baseline, 3-months post-surgery, 3-months post-stoma reversal and 12-months post-surgery	None	Qualitative interviews and surveys administered Median time between primary operation and stoma reversal was 4-months. “Although from a surgeon’s point of view the reversal of a stoma is a minor procedure, it has a significant negative impact on the patient’s daily lives” (1211). No change in QOL reported over the time frame of the study. Improvements reported in body image and leisure activities. Patients’ expectations were not met due to gastrointestinal symptoms persisting. Increased number of complaints about the hospital and the medical staff.
Knobf et al. 2007	Across the continuum	Narrative review	None	Strong evidence to support positive effects of exercise on physical and psychological wellbeing.

Appendix B: Information Sheet for focus group participants



Self-management Support in Cancer Care

Pilot Study

Phase One



This research is being led by researchers from the University of Otago, Wellington.

Information sheet



Thank you for showing an interest in this research. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you of any kind and we thank you for considering our request.



Who is doing this study?

This study is being led by researchers at the University of Otago in Wellington.

What are the aims of the study?

Due to improvements in cancer screening and treatment, the cancer journey often lasts many years for survivors who routinely manage cancer-related side-effects and sometimes complex medication regimes.

Research is needed to identify and evaluate new supportive care approaches that can better enable individuals and families/whānau to work in partnership with health professionals during cancer treatment and survivorship. The proposed study evaluates an integrated model of care, borrowed from chronic care, and transplanted to the cancer treatment context, to support people to fit cancer treatment into their lives. It will involve self-management and care planning support provided during outpatient cancer treatment for New Zealanders affected by cancer.

During this first phase of the study, the researchers are interested in your experience of cancer, support and coping at home. The next phase of the study takes place in the outpatient clinic in Wellington trying out the intervention in order to help people who are in the treatment phase of the cancer journey.

What does this part of the study involve?

You will be asked to participate in a 1-hour focus group with up to nine other people affected by cancer, and a researcher, which will be recorded.

You will be asked if you want your whānau/support people to participate in this. You do not have to answer all the questions, and you may leave the focus group at any time. We would also like to collect information on you including: your age, gender and ethnicity. The name/s of everyone participating in the focus group will be anonymised for the report and your name will not be linked to any comments in reports of the research. You will be provided with a \$30 petrol voucher as a contribution toward your travel expenses.

Participation in this study is voluntary (your choice). You may withdraw from participation in this project at any time. This will have no affect on your future health care.

If you withdraw, the information on you, and the interview you participated in will not be used in the research.

If you do participate the results of the project may be published but you will not be named and every effort will be made to ensure that you are not identified in any reported data. Information about your age, gender and ethnicity will be used to describe the people who participated in the research.

It will be used collectively and will in no way identify you as an individual. Transcripts and audio recordings will be kept on password protected computers and in locked filing cabinets for five years, at which time they will be destroyed by Dr Sarfati. You are most welcome to request a copy of the results of the project should you wish.

Ethics Approval

This study has received ethical approval from the Central Health and Disability Ethics Committee, which reviews regional studies, and has ethics reference number 12/CEN/12.

If you have any questions about the research contact:

Inga O'Brien, PhD Candidate

☎ 04 918 6549 or 04 918 6040

✉ obrin889@student.otago.ac.nz

University of Otago, Wellington

Associate Professor Diana Sarfati

☎ 04 918-6042 or 04 918 6040;

✉ Diana.sarfati@otago.ac.nz

University of Otago, Wellington

Associate Professor Louise Signal,

☎ 04 918-6477 or 021 0324 720

✉ louise.signal@otago.ac.nz

University of Otago, Wellington



Appendix C: Consent Form for phase one focus group participants

Consent form



If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:

Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

I have read and understood the information sheet explaining this research.

I have had the opportunity to talk about the research and ask questions.

I am satisfied with the answers I have been given.

I understand that my participation is voluntary and that I can withdraw from this research at any time.

I understand that I will not be named and that every effort will be made to ensure that I am not identified in any reported data.

I know whom to contact if I have any questions about this research.



I agree to take part in this research.

YES ☐ NO ☐

Please tick the option that applies to you.



I agree to allow the focus group or interview with me to be recorded.

YES ☐ NO ☐

Please tick the option that applies to you.

I hereby consent to take part in this study.

(First Name/Surname)

Signature

Date

Project explained by

Initials

Date

Note: Copies of consent forms will be given to you.



Participant demographic information



We would like to collect a few details for statistical purposes. This information will assist us describe the group of people who took part. No individual names will be used in any reports.



Gender, are you

☐

MALE

☐

FEMALE



When were you born?

DAY

MONTH

YEAR



Which ethnic group do you belong to? *(tick the box or boxes that apply to you)*

☐

New Zealand European

☐

Niuean

☐

Māori

☐

Chinese

☐

Samoaan

☐

Indian

☐

Cook Island Māori

☐

Other *(such as Dutch, Japanese, Tokelauan)*

☐

Tongan

If other please state

Thank you.

This research is being led by researchers from the University of Otago, Wellington.

Inga O'Brien, PhD Candidate

☎ 04 918 6549 or 04 918 6040

✉ obrin889@student.otago.ac.nz

University of Otago, Wellington

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✉ Diana.sarfati@otago.ac.nz

University of Otago, Wellington

Associate Professor Louise Signal,

☎ 04 918-6477 or 021 0324 720

✉ louise.signal@otago.ac.nz

University of Otago, Wellington



Appendix D: Focus group discussion guide

Outline process (topics to be discussed) and inform P [Participant] of rights (confidentiality, right to refuse to answer questions etc). Give P opportunity to ask any questions. Thank P for agreeing to take part.

Ice breaker - 20 mins (including intro above)

This PhD research evaluates a supportive care program that may be practically useful for people coping with cancer treatment side-effects and other long-term conditions now and into the future. I'd like to start out with questions about your cancer experiences.

- How would you describe how "cancer" has impacted on life for you during treatment?
- What did you worry about and how did you manage?
- Would you describe the cancer experience for you and/or your whānau or support people as long-term or ongoing?
- What are you doing to cope with ongoing cancer-related side effects, if any?

Self-Management Support Acceptability – 20 mins

Support can help people cope with cancer treatment side-effects and co-occurring conditions. This pilot study explores whether a type of support, self-management support, may be usefully provided in the outpatient clinic setting.

Read vignette.

Here's a specific example of self-management... John is feeling more unwell and is finding his usual jobs difficult to maintain. He is the main breadwinner for his family. The self-management person is part of the cancer team and talks to John privately, for just a short time, while he is in the day ward, about how he is going in fitting 'cancer' into everyday life at home. Self-management support encourages individuals to discuss what is most important to them at the time with a view to dealing with practical concerns. The coach reflects John's concerns and discusses with him things other people have tried. John and the self-management person collaboratively develop a plan that will work for him and his family or whānau. A written care plan is provided to John. It includes his goals. It may be of use at the time and/or when treatment ends. This may help John develop the confidence and skills to weave together what has happened in treatment with impacts at home and is an example of self-management.

Do you think this type of program might be useful? Why? Why not?

- What are your first impression views on self-management support provided during outpatient cancer treatment given that self-management support attempts to aid and inspire patients and caregivers to become better problem-solvers?

Self-Management Support Feasibility – 10 mins

Few studies identify the best time and place to provide support during a cancer journey.

- In your opinion, when is the ideal time to provide support considering the ups and downs of cancer diagnosis and treatment? Why?
- Where would be the best place to intervene with the patient/whānau to provide support?

- How do you see these sessions taking place? Who would provide the program? Who would be invited to participate, etc.?

Closing – 10 mins

Give a short summary (2 or 3 minutes) of the key questions and the big ideas that emerged from the discussion. Tie the summary to the purpose of the focus group. Then ask:

1. Is this an adequate summary?
2. How well does that capture what was said here?
3. Do you have any further comments?

Kia ora and thank you for sharing your views with me. Your input will help in the support of individuals and families/whānau affected by cancer in the future.

If this discussion has brought up anything distressing for you please don't be shy about contacting the Cancer Society Information Nurses on 0800 CANCER or your care coordinator or your doctor. We will be around to chat as well. Help yourselves to refreshments and I will hand out some vouchers.

Thank participant(s) and close.

Appendix E: Information sheet and consent form for key informant interviews

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of
OTAGO



Te Whare Wānanga o Ōtāgo

Self-management Support in Cancer Care Pilot Study

Stage One – Key Informant Interviews

HEALTH PROFESSIONAL INFORMATION SHEET

Thank you for showing an interest in this research. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you of any kind and we thank you for considering our request.

Who is doing this study?

This study is being led by researchers at the University of Otago in Wellington.

What are the aims of the study?

Due to improvements in cancer screening and treatment, the cancer journey often lasts many years for survivors who routinely manage cancer-related side-effects and sometimes complex medication regimes. Research is needed to identify and evaluate new supportive care approaches that can better enable individuals and families/whānau to work in partnership with health professionals during cancer treatment and survivorship. The proposed study evaluates an integrated model of care, borrowed from chronic care, and transplanted to the cancer treatment context, to support people experiencing health complexity to become better self-managers. A three-phase approach will explore self-management and care planning support delivered during outpatient cancer treatment for New Zealanders affected by cancer. During this first stage of the study, the researchers are interested in your views and experiences of cancer care, support and ways patients cope at home. The next stage of the study takes place in the outpatient clinic in Wellington piloting an intervention with people who are receiving cancer treatment.

What does this Stage One study involve?

You will be asked to participate in a 30-minute interview with a researcher which may be recorded and transcribed. You do not have to answer all the questions, and you may stop the interview at any time. We would also like to collect information on you including: your age, gender and ethnicity.

The name/s of all interviewees will be anonymised for the report and your name will not be linked to any comments in reports of the research.

Participation in this study is voluntary (your choice) and we appreciate your contribution pro bono (we cannot provide you with remuneration). You may withdraw from participation in this project at any time. If you withdraw, the information on you will not be used in the research.

If you do participate the results of the project may be published but you will not be named and every effort will be made to ensure that you are not identified in any reported data. Information about your age, gender and ethnicity will be used to describe the people who participated in the research. It will be used collectively and will in no way identify you as an individual. Transcripts and audio recordings will be kept on password protected computers and in locked filing cabinets for ten years, at which time they will be destroyed by Dr Sarfati. You are most welcome to request a copy of the results of the project should you wish.

Ethics Approval

This study has received ethical approval from the Central Health and Disability Ethics Committee, which reviews regional studies, and has ethics reference number 12/CEN/12.

If you have any questions about the research please contact:

Inga O'Brien, Ph (04) 918 6549; University of Otago Wellington; email:
obrin889@student.otago.ac.nz

or Research Fellow Diana Sarfati, Ph (04) 918-6042 or (04) 918 6040; University of Otago, Wellington; email: Diana.sarfati@otago.ac.nz

or Associate Professor Louise Signal, Ph (04) 918-6477 or Mobile 021 0324 720; University of Otago, Wellington, email: louise.signal@otago.ac.nz



Self-management Support in Cancer Care Pilot Study

Stage One – Key Informant Interviews

HEALTH PROFESSIONAL CONSENT FORM

- I have read and understood the information sheet explaining this research.
- I have had the opportunity to talk about the research and ask questions. I am satisfied with the answers I have been given.
- I understand that my participation is voluntary and that I can withdraw from this research at any time.
- I understand that I will not be named and that every effort will be made to ensure that I am not identified in any reported data.
- I know whom to contact if I have any questions about this research.
- I agree to take part in this research. Please circle the option that applies to you.

☐ YES

☐ NO

- I agree to allow the interview with me to be recorded. Please circle the option that applies to you.

☐ YES

☐ NO

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:

Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

I _____ hereby consent to take part in this study

(First Name/Surname)

Signature: _____ **Date:** _____

Project explained by: _____ **Initials:** _____ **Date:** _____

Note: Copies of consent forms will be given to you.

PARTICIPANT DEMOGRAPHIC INFORMATION

We would like to collect a few details for statistical purposes. This information will assist us describe the group of people who took part. No individual names will be used in any reports.

1. Are you: ☐ Male ☐ Female

2. When were you born?

Day _____ Month _____ Year you were born _____

3. Which ethnic group do you belong to? (tick the box or boxes that apply to you)

† ☐ New Zealand European

† ☐ Māori

† ☐ Samoan

† ☐ Cook Island Māori

† ☐ Tongan

† ☐ Niuean

† ☐ Chinese

† ☐ Indian

† ☐ Other (such as Dutch, Japanese, Tokelauan)

Please state if 'Other': _____

- I would like to receive a summary of the findings of the Stage One research. Please circle the option that applies to you.

☐ YES

☐ NO

- I would like a copy of the final findings of the research to be sent to me after the research is completed in 2014. Please circle the option that applies to you.

☐ YES

☐ NO

In order to send you a research summary could you please record your details below.

Name: _____

Address: _____

Email: _____

Signature: _____ **Date:** _____

Thank you

This research is being led by researchers from the University of Otago-Wellington.

If you have any questions about the research please contact:

Inga O'Brien, Ph (04) 918 6549; University of Otago Wellington; email:
obrin889@student.otago.ac.nz

or Research Fellow Diana Sarfati, Ph (04) 918-6042; University of Otago, Wellington; email:
Diana.sarfati@otago.ac.nz

or Associate Professor Louise Signal, Ph (04) 918-6477, Mobile 021 0324 720 University of Otago,
Wellington, email louise.signal@otago.ac.nz

Appendix F: Discussion guide for key informant interviews

Introduce self. Give overview of the project. Outline process (topics to be discussed) and inform P [Participant] of rights (confidentiality, right to refuse to answer questions etc). Give P opportunity to ask any questions. Thank P for agreeing to take part.

Ice breaker - 10 mins (including intro above)

This PhD research evaluates a support program that may be practically useful for people coping with cancer treatment side-effects and other long-term conditions now and into the future.

- What is your experience of cancer as a long-term condition?
- Do you find many people have other health issues to deal with in addition to cancer?
- How do you work with people to manage these complex health stresses?
- What kinds of things have you found helped people to cope with these health stresses?

Self-Management Support Acceptability – 10 mins

Supportive care helps people cope with cancer treatment side-effects and co-occurring conditions. This pilot study explores whether a type of supportive care, self-management support, may be usefully provided in the outpatient clinic setting. Self-management describes how people manage and make sense of their lives, in the context of physical, environmental, spiritual and social influences. However, self-management support encourages individuals to discuss what is most important to them at this time, promotes collaborative problem-solving and decision-making, considers an array of possible actions in the face of the reality of changing life circumstances, and attempts to motivate individuals and whānau to take action to reach their own self-determined goals.

- What is your experience of supportive care?
- What are your first impression views on self-management support provided during outpatient cancer treatment given that self-management support attempts to aid and inspire patients and caregivers to become better problem-solvers?
- What would you want to know in order to measure the acceptability of a self-management support programme?

Self-Management Support Feasibility – 10 mins

Few studies identify the best time and place to provide support during a cancer journey.

- In your opinion, when is the ideal time to provide supportive care considering the ups and downs of cancer diagnosis and treatment? Why?
- Where would be the best place to intervene with the patient/whānau to provide supportive care?
- How do you see these sessions taking place? Who would be invited to participate, etc.?

Self-Management Support Utility – 10 mins

It is important to evaluate tools and approaches for working in partnership from the perspective of both the patient and clinician.

- Given your role, what and how would you like to see the outcomes of a supportive care intervention measured?

Closing – 5 mins

I just want to ask one more question

If you were in charge, what would you do to incorporate more support into cancer care? **Thank participant(s) and close.**

Appendix G: Thematic development

	Conceptual Framework (Index) for study of self-management support during cancer care					
			Frame			
1	Personal details			4	Supportive care	
1.1	Demographic			4.1	Bridges	
1.2	Cancer journey			4.2	Cultural relevance	
1.3	Partnership status			4.3	Spiritual relevance	
1.4	Living arrangements			4.4	Organisations	
1.5	Employment			4.5	Roles	
1.6	Health			4.6	Timing	
1.7	Other			4.7	Location	
1.8	Recurrence			4.8	What works	
				4.8.1		Support groups (Maori cancer-specific)
2	Cancer as a life-changing experience					
2.1	Crisis		Emotion	5	Expectations of healthcare practitioners	
2.2	Treatment		Physical	5.1	Cancer care	
2.3	Side-effects		Physical	5.2	Information	
2.4	Chronic impacts		Physical	5.3	Empathy	
2.5	"getting through"		Physical	5.4	Building relationships	
2.6	Coping		Emotion	5.5	Holistic care	
2.7	Hard to ask for help		Social	5.6	Values consideration	
2.8	Scared		Emotion	5.7	Distrust of HCP and system	
2.9	Identity		Spiritual	5.8	Discharge planning	
3	Concerns/worries outside of treatment			6	Recovery	
3.1	Family/Whanau		Social	6.1	Normality	Survivorship work
3.2	Other relationships		Social	6.2	Challenges	Survivorship work
3.3	Physical limitations		Physical	6.3	Ongoing care	Survivorship work
3.4	Worry		Emotional	6.4	Adjustment	Survivorship work

3.5	Financial		Social		7	Self-management support	
3.6	Work roles		Social		7.1	Knowledge about	
3.7	Life roles		Social		7.2	Views about	
3.8	Mana		Spiritual		7.3	Acceptability	
3.9	Home		Physical		7.4	5 core skills	resource utilisation
					7.4.1		healthcare partnerships
					7.4.2		taking action in order to manage health complexity
					7.4.3		collaborative decision-making
					7.4.4		problem-solving
					7.4.5		
					8	Other key issues (not covered above)	
					8.1	co-morbidity	
					8.2	people on their own	
					8.3	Travel for treatment	
					8.4	Suicidal ideation	

Appendix H: Information sheet for phase two pilot study participants



Self-management Support in Cancer Care

Pilot Study



This research is being led by researchers from the University of Otago, Wellington.

Information sheet



Thank you for showing an interest in this research. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you of any kind and we thank you for considering our request.



Who is doing this study?

This study is being led by researchers at the University of Otago-Wellington.

What are the aims of the study?

Due to improvements in care, the cancer journey often lasts many years for survivors who routinely manage cancer-related side-effects. Research is needed to identify and evaluate support that can help individuals and families/whānau partner with health professionals to support care outside the hospital.

This research study explores a way to support people with coping and managing at home. This project may help individuals and families/whānau affected by cancer now and in the future to better cope at home and incorporate the cancer experience into their everyday lives and routines.

We call this a pilot because it is the beginning of the study and the aim is to find out if the programme is acceptable and useful. The pilot study is an important part of the research process as it will help make future larger studies flow smoothly.

What does this study involve?

This research is being undertaken at the outpatient clinic in Wellington. Fifty people will be invited to participate. If you choose to participate, you will be randomly assigned to one of two groups.

One of these groups will receive 3 brief self-management support sessions for approximately 30 minutes during a usual appointment at the outpatient clinic (after you see the doctor). The second group will receive standard supportive care by the outpatient staff as per usual practice. Group allocation will not have any additional impact on the standard health care that you will be given. In addition, each participant will be asked to participate in two interviews with a researcher which will be recorded.

The first interview will likely take place before an appointment toward the middle of your time receiving treatment and should take approximately 20 minutes. You will be asked if you want your whānau/support people to participate in this. You do not have to answer all the questions, and you may stop the interview at any

time. We would also like to collect information on you including: your age, gender, ethnicity and health status. The name/s of everyone participating in the research will be anonymised and names will not be linked to any comments in reports of the research. For the first interview we contribute \$20 in petrol vouchers toward your travel costs.

The second assessment will occur prior to the usual 6-week follow-up appointment that marks the end of outpatient treatment. Similar questions to the first assessment will be asked and you will also need to complete a patient experience survey form at home. You will be sent \$30 in petrol vouchers once you have sent back the patient experience survey form. Participation in this study is voluntary (your choice). You may withdraw from participation in this project at any time.

This will have no affect on your future health care. If you withdraw, the information on you, your consultation and the interview you participated in will not be used in the research. If you do participate the results of the project may be published but you will not be named and every effort will be made to ensure that you are not identified in any reported data. Information about your age, gender, ethnicity and health status will be used to describe the people who participated in the research. It will be used collectively and will in no way identify you as an individual. Transcripts and audio recordings will be kept on password protected computers and in locked filing cabinets for ten years, at which time they will be destroyed by Dr Sarfati. You are most welcome to request a copy of the results of the project should you wish.

Ethics Approval

This study has received ethical approval from the Central Health and Disability Ethics Committee, which reviews regional studies, and has ethics reference number 12/CEN/12.

If you have any questions about the research contact:

Inga O'Brien, PhD Candidate
☎ 04 918 6549 or 04 918 6040
✉ obrin889@student.otago.ac.nz
University of Otago, Wellington



Appendix I: Consent form for phase two pilot study participants

Consent form



We would like to collect a few details for statistical purposes.
This information will assist us describe the group of people who took part.
No individual names will be used in any reports.

I have read and understood the information sheet explaining this research.

I have had the opportunity to talk about the research and ask questions.

I am satisfied with the answers I have been given.

I understand that my participation is voluntary and that I can withdraw from this research at any time.

I understand that I will not be named and that every effort will be made to ensure that I am not identified in any reported data.

I know whom to contact if I have any questions about this research.



I agree to take part in this research.

YES ☐ NO ☐

Please tick the option that applies to you.



I agree to allow the sessions I attend to be recorded.

YES ☐ NO ☐

Please tick the option that applies to you.



I agree for the information collected as part of this research project to be stored for ten years and that de-identified data be available for use to inform a future research study.

YES ☐ NO ☐

Please tick the option that applies to you.



Consent form



If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:

Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz



I agree for my whānau/support person/s to be present during my interviews.

YES ☐ NO ☐

Please tick the option that applies to you.



I agree to the researchers accessing my medical file for the purposes of care planning.

YES ☐ NO ☐

Please tick the option that applies to you.



I agree that if clinical issues arise, these will be referred to my medical team.

YES ☐ NO ☐

Please tick the option that applies to you.

I

(First Name/Surname)

hereby consent to take part in this study.

Signature

Date

Project explained by

Initials

Date

Note: Copies of consent forms will be given to you.



Participant demographic information



We would like to collect a few details for statistical purposes.
This information will assist us describe the group of people who took part.
No individual names will be used in any reports.



Gender, are you

☐

MALE

☐

FEMALE



When were you born?

DAY

MONTH

YEAR



Which ethnic group do you belong to? *tick the box or boxes that apply to you*

☐

New Zealand European

☐

Niuean

☐

Māori

☐

Chinese

☐

Samoaan

☐

Indian

☐

Cook Island Māori

☐

Other *(such as Dutch, Japanese, Tokelauan)*

☐

Tongan

If other please state

I would like to receive a summary of the findings of the research.

YES

☐

NO

☐

Please tick the option that applies to you.

I would like a copy of the full findings of the research to be sent to me after the research is completed in 2014.

YES

☐

NO

☐

Please tick the option that applies to you.



Consent form



Thank you for your
participation in
our survey.

In order to send you a research summary could you please record your details below.

Name:

Address:

Email:

Signature Date



I would like my GP to be informed that I am
a participant in this research study.

YES

☐

NO

☐

Please tick the option that applies to you.

GP Name:

GP Address:

Signature Date

Thank you

This research is being led by researchers from the University of Otago, Wellington.

Inga O'Brien, PhD Candidate

☎ 04 918 6549 or 04 918 6040

✉ obrin889@student.otago.ac.nz

University of Otago, Wellington

Associate Professor Diana Sarfati

☎ 04 918-6042 or 04 918 6040;

✉ Diana.sarfati@otago.ac.nz

University of Otago, Wellington

Associate Professor Louise Signal,

☎ 04 918-6477 or 021 0324 720

✉ louise.signal@otago.ac.nz

University of Otago, Wellington



Appendix J: Authorisation to release information for research study purposes

There is a study being run to support individuals and families/whānau affected by cancer to better cope at home during treatment and recovery. The study leader can discuss the study with you at hospital, by phone or at your next appointment if you wish to know more. If you do wish for me to ask her to call you in a few days or meet with you, written consent is required.

Consent to Release Information for Research Study Recruitment

I _____

(Patient's Full Name)

Authorise _____

(Referring Clinician's Name)

To give my name, contact details and study eligibility information to Inga O'Brien (PhD Candidate/Researcher) for the purposes of giving me more information about the University of Otago, Wellington- based research study called: *Self-management support in cancer care pilot study*.

I give my consent to release my name, contact details and study eligibility information knowing that:

- I do not have to sign this consent. If I do not sign it, it will not affect my treatment and my information will not be released for research.
- I can cancel this authorisation any time in writing. However, if I cancel it, the researcher may already have been given the information but they will not use it in the future.
- This research conforms to the New Zealand Privacy Act.

Patient's Signature

Date

Note: The researcher will need to meet with patient at the time of the surgical follow-up appointment and two other times.

Name of person completing this form:

Eligible for study:

☐ Confirmed diagnosis of COLORECTAL
CANCER

**Has the patient agreed to be
contacted by the researcher?**

☐ Yes, please complete Section B.
☐ No, please complete Section C.

B. Participant Details:

First Name:

Surname:

Preferred name:

Ethnicity:

Sex: M / F

Comorbidities:

☐ Diabetes

☐ Heart disease

☐ Other (specify)

Preferred contact:

☐ At hospital

☐ By phone

Contact phone number: _____

☐ In person at next appointment

Next appointment scheduled for _____

C. Decliner Details: To help us know if we're missing a particular group of people, it would be helpful to have age, sex & ethnicity recorded, if the person is happy with this.

Age:

Sex: M / F

Ethnicity:

Reason for declining (if given):

D. Other comments:

Signed:

Date:

Appendix K: Baseline and follow-up assessment forms

SF12v2

These questions ask for your views on how you are feeling now and how well you are able to do your usual activities. Answer every question by ticking or filling in one of the answers. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b Climbing <u>several</u> flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a <u>Accomplished less</u> than you would like	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b Were limited in the <u>kind</u> of work or other activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a <u>Accomplished less</u> than you would like	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b Did work or activities <u>less carefully than usual</u>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Have you felt calm and peaceful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b Did you have a lot of energy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c Have you felt downhearted and depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Resilience & Activation Scales

Here are some statements that people sometimes make when they talk about their health. Please indicate how true they are for you for the first two and how much you agree or disagree with each statement for the remaining ones after the first two. *Your answers should be what is true for you and not just what you think anyone around here wants you to say.*

1. I am able to adapt when changes occur.	Not true at all	Rarely true	Sometimes true	Often true	True nearly all the time
2. I tend to bounce back after illness, injury or other hardships.	Not true at all	Rarely true	Sometimes true	Often true	True nearly all the time

If any of the next statements do not apply to you, circle N/A.

1. When all is said and done, I am the person who is responsible for taking care of my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2. Taking an active role in my own health care is the most important thing that affects my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3. I am confident I can help prevent or reduce problems associated with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4. I know what each of my prescribed medications do	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6. I am confident that I can tell a doctor concerns I have even when he or she does not ask.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7. I am confident that I can follow through on medical treatments I may need to do at home	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8. I understand my health problems and what causes them.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9. I know what treatments are available for my health problems	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
11. I know how to prevent problems with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
12. I am confident I can figure out solutions when new problems arise with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

Self-Efficacy for Managing Chronic Disease 6-Item Scale

These next 6 questions are also about how confident you are in doing certain activities.

I would like to know how confident you feel in doing these specific activities as indicated by your choice of a number 1 - 10 that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

1 2 3 4 5 6 7 8 9 10

Not at all confident

Totally confident

2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

1 2 3 4 5 6 7 8 9 10

Not at all confident

Totally confident

3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

1 2 3 4 5 6 7 8 9 10

Not at all confident

Totally confident

4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

1 2 3 4 5 6 7 8 9 10

Not at all confident

Totally confident

5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

1 2 3 4 5 6 7 8 9 10

Not at all confident

Totally confident

6. How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

1 2 3 4 5 6 7 8 9 10

Not at all confident

Totally confident

Open-ended questions – please record answers using an audio recorder or legible written responses

- 1. What are the main things you do now to support your recovery and wellbeing at home?**

- 2. If you could change one thing about managing life during cancer treatment while at home, what would it be?**

- 3. What support programmes, if any, have been or would be of value to you?**

- 4. Any extra information you can provide about how to make cancer care better is very useful, is there anything else you want to share about your experience or that of others in your life affected by cancer?**

The Distress Thermometer

First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Extreme Distress

10

9

8

7

6

5

4

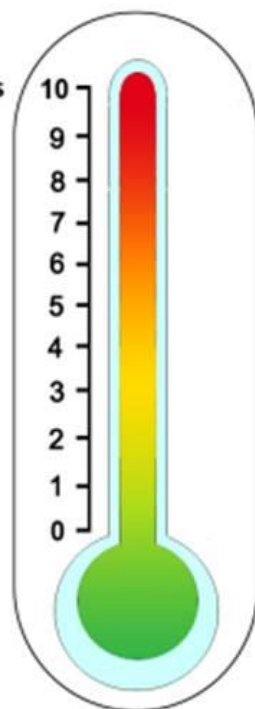
3

2

1

0

No Distress



Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES NO

Practical Problems

Child Care

Housing

Insurance/financial

Transportation

Work/school

Family Problems

Dealing with children

Dealing with partner

Dealing with close

Friend/relative

Emotional Problems

Depression

Fears

Nervousness

Sadness

Worry

Loss of interest in usual activities

Spiritual/religious concerns

YES NO

Physical Problems

Appearance

Bathing/dressing

Breathing

Changes in urination

Constipation

Diarrhoea

Eating

Fatigue

Feeling Swollen

Fevers

Getting around

Indigestion

Memory/concentration

Mouth sores

Nausea

Nose dry/congested

Pain

Sexual

Skin dry itchy

Sleep

Tingling in hands/feet

Other problems

Appendix L: Additional follow-up assessment components

For Intervention Group ONLY – Acceptability of intervention

Please circle a response to indicate how much you agree or disagree with the following statements.

1. I am satisfied with the self-management program sessions.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2. I found the sessions helpful.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3. The sessions were long enough.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4. There were enough sessions.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5. I felt the study was delivered by someone who was interested in me as a person.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6. I was able to make useful changes with the help of the sessions.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7. The changes have improved the way I am feeling.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8. I am confident that these changes will be lasting.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9. I would recommend these sessions to a friend.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

Cancer Control Council of New Zealand: 2009 Patient Survey

Cancer Care Survey

New Zealand's national health system "customers" include patients and their carers. The Cancer Control Council of New Zealand Patient Survey has been developed to gain information about your experience as a "customer" of health services so they can be improved.

What is the survey about?

This survey is about your experiences of the cancer care services you have had contact with over the last 12 months. This may have involved care at your local hospital or one of the six regional cancer centres. We are mostly interested in the care you received at the hospital or clinic where you had the majority of your cancer treatment.

Completing the survey


There are no right or wrong answers – it is your opinions about your health care experience that are important to the Cancer Control Council.

When completing each question, please mark the box to indicate your response as shown in the example to the right.

Please use a blue or black pen to mark your responses.

Sometimes you will find the box you have marked has an instruction to go to another question.

By following the instructions carefully you will be able to skip questions that do not apply to you.

Don't worry if you make a mistake or wish to change a response; simply cross out the error and mark the correct box like this: 

Please do not write your name or address anywhere on the questionnaire.

EXAMPLE ONLY

70. In the past 12 months, did you receive all of the services you thought you needed for your cancer treatment?

- ☐ Never
- ☐ Sometimes
- ☒ Usually
- ☐ Always

How will my privacy be protected?

Responses to this survey will be treated in the strictest confidence and no identifying information will be given to the Ministry of Health, the hospital or health service you attended, your doctor or other health provider. Your response will not affect any future services that may be provided to you through the New Zealand national health system.

After all surveys are processed, identifying information will be destroyed. Survey responses will be de-identified and aggregated into reports. These will be provided to the Ministry of Health and the District Health Boards, who will use them to help improve health services.

If you need to make a formal complaint

This survey is not the best way to make a formal complaint, as the researchers will not be able to help you resolve it. If you would like to make a formal complaint about your experience, please contact the relevant health facility directly.

Alternatively, you may visit <http://www.hdc.org.nz/complaints/making-a-complaint> for more advice on your options.

Contact the Cancer Control Council

If you require further information please contact the Cancer Control Council **0800 162 002** or (04) 815 9800

When you have finished

Please remove the covering letter by tearing along the perforated line.

Place the completed survey in the "Reply Paid" envelope and post it. You do not have to use a stamp.

If you have misplaced the "Reply Paid" envelope, just use a plain envelope – no stamp necessary, and address to:
**2009 Patient Survey c/o Cancer Control Council
Freepost 56866
PO Box 210015
Laurence Stevens Drive
Manukau 2154**

Your Cancer Care Experience

1. Our records show that you received cancer care services or treatment in the past 12 months. Is that right?

- ☐ Yes, currently receiving or have received cancer treatment
- ☐ Yes, but have ONLY received follow-up care in the past 12 months
- ☐ No, have not received cancer care in the past 12 months

➔ Please do not complete this survey

About Your Diagnosis

2. When were you first told of your cancer diagnosis?

- ☐ Less than 6 months ago
- ☐ Between 6-12 months ago
- ☐ Between 1 and 2 years ago
- ☐ Between 2 to 5 years ago
- ☐ More than 5 years ago

3. Who first told you of your cancer diagnosis?

- ☐ Family doctor
- ☐ Cancer specialist
- ☐ Surgeon
- ☐ Someone else

4. Were you told of your diagnosis in a sensitive manner?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely

5. When you were first told of your illness, did someone put you in touch with other health care professionals who could help you with anxieties and fears or issues?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely
- ☐ I had no anxieties or fears

Planning Your Treatment

6. Sometimes more than one doctor, nurse or other health care professional helps patients plan their cancer treatment. Who was involved in most of your treatment planning?

(Please mark only one)

- ☐ Family doctor
- ☐ Cancer specialist doctor
- ☐ Surgeon
- ☐ Nurse / Cancer Nurse Specialist
- ☐ Cancer care co-ordinator
- ☐ Someone else

7. Did someone discuss different treatments for cancer with you?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely

8. Did you understand the information you were given about the different treatment options?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely

9. Were you given enough information about cancer treatments?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely

10. Was the information you were given about cancer treatment or its side-effects provided at the time you needed it?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

Planning Your Treatment (continued)

11. Were you involved in decisions about your care as much as you wanted?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely

12. Did your doctors, nurses or other health care professionals take your family or living situation into account in planning for your treatment?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely

13. Did your family or friends have enough opportunity to be involved in your care and treatment?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely

14. Do you think the doctors, nurses or other health care professionals knew enough about therapies for treating cancer?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely

15. If you had questions about clinical trials or new treatments for your cancer, did you feel comfortable talking with the staff about them?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely
- ☐ I didn't have questions

16. Was your case reviewed by a number of specialists / health professionals consulting together (a multi-disciplinary team) before the final treatment plan was finally decided?

- ☐ Yes
- ☐ No
- ☐ No treatment plan completed
- ☐ Not sure

Planning Your Treatment (continued)

17. After you knew what your treatment was going to be, do you feel you had to wait too long to get your first appointment for treatment?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely

18. If you had to wait for your first appointment for treatment, did someone explain why?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely
- ☐ Didn't have to wait

19. If you had to travel for any tests or treatments, did your doctors, nurses or other staff consider your travel concerns when planning for your treatment?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely
- ☐ Didn't have to travel

About Your Tests

20. Did the doctors, nurses, or other health care professionals explain why you needed tests in a way you could understand?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely
- ☐ Didn't have tests

21. After the tests were done, did someone explain the results in a way that you could understand?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely
- ☐ Didn't need explanation
- ☐ Never received results
- ☐ Didn't have tests

About Your Surgery

22. Did you have surgery for your cancer?

- ☐ Yes
☐ No → [Go to Question 26](#)

23. Where did you have your surgery?

- ☐ Auckland City Hospital
☐ Waikato Hospital
☐ Palmerston North Hospital
☐ Wellington Hospital
☐ Christchurch Hospital
☐ Dunedin Hospital
☐ At another hospital or clinic (not listed above)
(Please write the name of the hospital or clinic in the space below)
-

24. Were you given enough information about how long you would have to wait until the day of your surgery?

- ☐ Not at all
☐ Somewhat
☐ For the most part
☐ Definitely
☐ Didn't have to wait

25. Were the results of your surgery explained in a way you could understand?

- ☐ Not at all
☐ Somewhat
☐ For the most part
☐ Definitely

About Your Chemotherapy

26. Have you had outpatient chemotherapy during the past 12 months?

- ☐ Yes
☐ No → [Go to Question 34](#)

About Your Chemotherapy (continued)

27. Where did you have the majority of your chemotherapy?

- ☐ Auckland City Hospital
☐ Waikato Hospital
☐ Palmerston North Hospital
☐ Wellington Hospital
☐ Christchurch Hospital
☐ Dunedin Hospital
☐ At another hospital or clinic (not listed above)
(Please write the name of the hospital or clinic in the space below)
-

28. When you went for your chemotherapy, did you usually have your blood test(s) during the same visit?

- ☐ Yes
☐ No

29. How long did you usually have to wait from your scheduled appointment until your chemotherapy treatment?

- ☐ Less than 30 minutes
☐ Between 30 and 60 minutes
☐ Between 1 and 3 hours
☐ More than 3 hours

30. How often did you wait longer than expected for your chemotherapy treatment?

- ☐ Never
☐ Sometimes
☐ Usually
☐ Always

31. If you had to wait for your chemotherapy, do you think the staff did everything they could to make you feel comfortable?

- ☐ Never
☐ Sometimes
☐ Usually
☐ Always
☐ Didn't have to wait

About Your Chemotherapy (continued)

32. Did someone tell you how to manage any side effects of chemotherapy?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Didn't have side effects

33. Do you think the staff did everything they could to help you with your chemotherapy side effects?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Didn't have side effects

About Your Radiation Therapy

34. Have you had radiation therapy during the past 12 months?

- ☐ Yes
- ☐ No → [Go to Question 41](#)

35. Where did you have the majority of your radiation therapy?

- ☐ Auckland City Hospital
 - ☐ Waikato Hospital
 - ☐ Palmerston North Hospital
 - ☐ Wellington Hospital
 - ☐ Christchurch Hospital
 - ☐ Dunedin Hospital
 - ☐ At another hospital or clinic (not listed above)
- (Please write the name of the hospital or clinic in the space below)*
-

36. How long did you usually have to wait from your scheduled appointment until your radiation treatment?

- ☐ 15 minutes or less
- ☐ Between 15 and 30 minutes
- ☐ Between 30 and 45 minutes
- ☐ Between 45 and 60 minutes
- ☐ More than 60 minutes

About Your Radiation Therapy (continued)

37. How often did you wait longer than expected for your radiation treatment?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

38. If you had to wait for your radiation treatment, do you think the staff did everything they could to make you feel comfortable?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Didn't have to wait

39. Did someone tell you how to manage any side effects of radiation therapy?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Didn't have side effects

40. Do you think the staff did everything they could to help you with your radiation therapy side effects?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Didn't have side effects

Symptom Management

41. In the past 12 months, if you had pain, was it usually severe, moderate, or mild?

- ☐ Severe
- ☐ Moderate
- ☐ Mild
- ☐ Didn't have pain in the past 12 months

Symptom Management (continued)

42. Do you think the staff did everything they could to control your pain or discomfort?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Didn't have pain

43. Did you get enough information about possible changes in your physical appearance?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Doesn't apply

44. Did you get enough information about possible changes in your emotions?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Doesn't apply

45. Did you get enough information about your nutritional needs?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Doesn't apply

46. Did you get enough information about possible impact on your capacity to work or do your usual activities?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Doesn't apply

Symptom Management (continued)

47. Did you get enough information about possible changes in your energy level?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Doesn't apply

48. Were you offered counselling or support relating to issues such as concerns about cancer or coping at home or at work?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Doesn't apply

49. Did you get enough information about possible changes in your relationship with your spouse or partner?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Doesn't apply

50. Did you get enough information about possible changes in your sexual activity?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Doesn't apply

51. Did you want but NOT receive information about any of the following services? *(Mark all that apply)*

- ☐ Counselling / support (social workers, psychologists)
- ☐ Spiritual support
- ☐ Dietitian
- ☐ Speech therapist
- ☐ Occupational therapist
- ☐ Physical therapist
- ☐ Support groups
- ☐ Palliative care
- ☐ Dental practitioner
- ☐ Cancer Help-Line (0800 CANCER)
- ☐ Other

Symptom Management (continued)

52. Did you feel comfortable talking with the staff about complementary, alternative, or non-traditional therapies?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Doesn't apply

53. Did you use any additional treatment or remedies not prescribed by your doctor or treatment team since you received your cancer diagnosis?

- ☐ Yes
- ☐ No
- ☐ Not sure

Your Health Care Professionals

Where questions ask about your experience of care, your answer should be about the hospital or clinic where you received most of your cancer treatment.

54. In the past 12 months, how many different doctors have you had visits with for your cancer treatment?

- ☐ One
- ☐ Two
- ☐ Three
- ☐ Four or more

55. Did you know who was in charge of your care for each of your therapies?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

56. How well handled was the transfer of your case between specialist groups (care coordination)?

- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Very good
- ☐ Excellent
- ☐ No transfer between specialist groups

Your Health Care Professionals (continued)

57. In the past 12 months, after initial diagnosis, has someone at this hospital or clinic put you in touch with other doctors, nurses, or other health care professionals who could help you with anxieties and fears?

- ☐ Not at all
- ☐ Somewhat
- ☐ For the most part
- ☐ Definitely
- ☐ I had no anxieties or fears

58. How often were the doctors, nurses, or other health care professionals familiar with your medical history?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

59. How often were the doctors, nurses, or other health care professionals aware of your test results?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

60. How often were you given confusing or contradictory information about your health or treatment?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

61. How often did you know who to ask when you had questions about your health problems?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

Your Health Care Professionals (continued)

62. How often did you know what the next step in your care would be?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

63. Did you feel you could trust the doctors, nurses, or other health care professionals with confidential information?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

64. Did the doctor, nurses, or other health care professionals treat you with dignity and respect?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

65. Did you get as much help as you wanted in figuring out how to pay for any extra costs for your cancer care?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Doesn't apply

66. Did a doctor, nurse, or other health care professional go out of his or her way to help you or make you feel better?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

Your Health Care Professionals (continued)

67. If you had a visit with your family doctor in the past 12 months, did you feel your family doctor knew enough about your cancer care?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ No visit to family doctor in last 12 months

68. Did you feel that the doctors, nurses, and other health care professionals at this hospital or clinic did everything they could to treat your cancer?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

69. Overall, how would you rate the quality of care at this hospital or clinic over the past 12 months?

- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Very good
- ☐ Excellent

70. Would you recommend the doctors, nurses, and other health care professionals at this hospital or clinic to your family and friends?

- ☐ Definitely Yes
- ☐ Probably Yes
- ☐ Probably Not
- ☐ Definitely Not

Overall Impressions

Where questions ask about your experience of care, your answer should be about the hospital or clinic where you received most of your cancer treatment.

71. Do you feel you had enough privacy during your care?

- ☐ Yes, always
- ☐ Yes, sometimes
- ☐ No

Overall Impressions (continued)

72. In the past 12 months, did you receive all of the services you thought you needed for your cancer treatment?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

73. Overall, how would you rate the quality of all of your care in the past 12 months?

- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Very good
- ☐ Excellent

74. Were you given as much information as you wanted about your rights and responsibilities as a patient?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

75. Using any number from 0 to 10, where 0 is the worst hospital or clinic possible and 10 is the best hospital or clinic possible, what number would you use to rate this hospital or clinic?

Worst Possible Hospital or Clinic Best Possible Hospital or Clinic

0 1 2 3 4 5 6 7 8 9 10
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

76. Would you recommend this hospital or clinic to your friends and family?

- ☐ Yes, definitely
- ☐ Yes, probably
- ☐ No

Amenities

Where questions ask about your experience of care, your answer should be about the hospital or clinic where you received most of your cancer treatment.

Poor Fair Good Very Good Excellent

77. Ease of understanding directions and signs inside and outside this hospital or clinic

☐ ☐ ☐ ☐ ☐

78. Availability of parking

☐ ☐ ☐ ☐ ☐

79. Keeping noise levels to a minimum

☐ ☐ ☐ ☐ ☐

80. Was the entire department or clinic as clean as it should have been?

- ☐ Yes, definitely
- ☐ Yes, somewhat
- ☐ No

81. What areas of the department or clinic were not clean?

(Please fill in all that apply)

- ☐ Waiting area
- ☐ Registration desk area
- ☐ Examination area
- ☐ Treatment area
- ☐ Bathroom / toilets
- ☐ Vending machine area
- ☐ Hallways
- ☐ All areas were clean

Your Background

82. In general, how would you rate your health?

- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Very good
- ☐ Excellent

83. During the past month, how many days did illness or injury keep you in bed all or part of the day?

- | | |
|-------------------------------------|---|
| <input type="checkbox"/> None | <input type="checkbox"/> Four days |
| <input type="checkbox"/> One day | <input type="checkbox"/> Five-to-seven days |
| <input type="checkbox"/> Two days | <input type="checkbox"/> Eight-to-ten days |
| <input type="checkbox"/> Three days | <input type="checkbox"/> More than ten days |

84. On how many separate occasions did you attend this outpatient clinic in the past month?

- ☐ One
- ☐ Two
- ☐ Three
- ☐ Four
- ☐ Five to nine
- ☐ Ten or more
- ☐ Have not visited clinic in the past month

85. How many times in the last 12 months have you been in a hospital overnight or longer?

- ☐ 1 time
- ☐ 2 times
- ☐ More than 2 times
- ☐ Not in hospital overnight in this period

86. For this treatment you have been referring to, were/are you treated as a:

- ☐ Public patient (including ACC)
- ☐ Private patient / claiming against private health insurance
- ☐ Something else
- ☐ Not sure

Your Background (continued)

87. What was the highest level of education you completed?

- ☐ None
- ☐ Primary or less than year 12 at secondary school
- ☐ Secondary school qualification (e.g. School Certificate, Sixth Form Certificate, NCEA, University Entrance Bursary / Scholarship)
- ☐ Trade or technical certificate or diploma
- ☐ University graduate
- ☐ Post graduate / higher degree
- ☐ Don't know / unsure

88. Which ethnic group or groups do you belong to?

- | | |
|---|--|
| <input type="checkbox"/> New Zealand European | <input type="checkbox"/> Chinese |
| <input type="checkbox"/> Māori | <input type="checkbox"/> Indian |
| <input type="checkbox"/> Samoan | <input type="checkbox"/> Other, such as Dutch, Japanese, Tokelauan |
| <input type="checkbox"/> Cook Island Māori | <i>(Please specify)</i> |
| <input type="checkbox"/> Tongan | |
| <input type="checkbox"/> Niuean | |

89. What language do you normally speak at home?

- ☐ English
- ☐ Māori
- ☐ Samoan
- ☐ NZ Sign language
- ☐ Other e.g. Gujarati, Cantonese, Greek *(Please specify)*

90. In which country / region were you born?

- ☐ New Zealand
- ☐ Australia
- ☐ England
- ☐ Scotland
- ☐ South Africa
- ☐ China (People's Republic of)
- ☐ Samoa
- ☐ Cook Islands
- ☐ Other *(Please Specify using current name of the country)*

Your Background (continued)

91. What is your household's annual income after tax
(include income from all sources)

- ☐ Less than \$5,000
- ☐ \$5,001–\$10,000
- ☐ \$10,001–\$20,000
- ☐ \$20,001–\$30,000
- ☐ \$30,001–\$40,000
- ☐ \$40,001–\$50,000
- ☐ \$50,001–\$60,000
- ☐ \$60,001–\$80,000
- ☐ \$80,001–\$100,000
- ☐ \$100,001–\$120,000
- ☐ \$120,001–\$150,000
- ☐ \$150,001 or more
- ☐ Prefer not to answer

92. Are you male or female?

- ☐ Male
- ☐ Female

95. If you could change one thing about your cancer care services, what would it be?

96. Please provide any other comments about your cancer journey.

Thank you for taking the time to complete this questionnaire! Your answers are greatly appreciated.

Your Background (continued)

93. To which age group do you (the patient) belong?

- ☐ 15 to 19 years
- ☐ 20 to 29 years
- ☐ 30 to 39 years
- ☐ 40 to 49 years
- ☐ 50 to 59 years
- ☐ 60 to 69 years
- ☐ 70 to 79 years
- ☐ 80 years or older

Final

94. Did the patient complete this survey?

- ☐ Yes – I completed the survey myself
- ☐ Yes – but I completed the survey with the help from someone else
- ☐ No – someone completed this survey for me

Appendix M: Calculated scores on outcome measures by participant

	Partners in Health Scale (PIH)		Resilience Scale (CD-RISC)		Patient Activation Measure (PAM)		Chronic Disease Self-Efficacy Scale		Distress Thermometer (DT)	
Group assignment	Baseline	Follow-up	Baseline	Follow-up	Baseline	Follow-up	Baseline	Follow-up	Baseline	Follow-up
Intervention	6.9	6.4	5	5	43.4	68.5	5.3	5.2	1	5
Intervention	7.5	6.7	8	8	86.3	75.3	8.7	7.3	3	1
Intervention	7.2	5.2	5	3	80	40.1	6.8	3.5	2	5
Intervention	3.2	5.2	6	6	56.4	56.4	7	7	1	1
Intervention	7.2	6.2	6	5	40.1	47.4	5.5	4.2	8	3
Intervention	4.2	6.3	8	7	47.4	68.5	8.3	6.5	5	2
Intervention	6.2	6.7	8	7	70.8	91.6	3.3	8.3	2	8
Intervention	6.8	6.5	5	6	60	56.4	6.8	6.8	5	4
Intervention	7.5	7.7	8	8	56.4	77.5	10	9	0	0
Intervention	7	7	8	0	45.2	45.2	8.5	8.5	2	0
Intervention	4.5	6.8	3	4	40.1	60	4.8	3.5	9	3
Intervention	6.7	6.7	8	6	70.8	63.2	7.3	6	3	6
Intervention	7.8	7.8	8	8	80	80	5.5	8	0	0
Intervention	4	6.2	4	4	60	68.5	6.5	6.5	0	0
Control	7.2	7.2	8	8	68.5	68.5	8.8	9	2	3
Control	6.5	7.8	8	8	68.5	68.5	8.2	10	0	0
Control	7.5	7.1	7	8	68.5	66	7	8	0	0
Control	7.7	7.9	8	8	82.8	100	7.5	9.3	0	0
Control	6.58	7.9	8	8	70.8	100	6	9.7	8	2
Control	6.7	6.9	5	7	56.4	75.3	7.2	7.2	4	2
Control	7	7	8	8	60	80	5.8	1.8	1	3

	Partners in Health Scale (PIH)		Resilience Scale (CD-RISC)		Patient Activation Measure (PAM)		Chronic Disease Self-Efficacy Scale		Distress Thermometer (DT)	
Group assignment	Baseline	Follow-up	Baseline	Follow-up	Baseline	Follow-up	Baseline	Follow-up	Baseline	Follow-up
Control	6.9	6.9	6	8	56.4	70.8	8.2	8.8	0	1
Control	6.6	7.5	6	6	52.9	68.5	6	9.3	2	0
Control	7	6.8	6	7	56.4	45.2	8.5	7.3	5	8
Control	7.6	7.4	8	7	56.4	75.3	8	9	1	1
Control	4.9	4.5	4	4	63.2	63.2	7	7	1	1
Control	6.8	6.8	8	8	52.9	56.4	8	8	0	0

Appendix N: Example Flinders Care Plan

Date: 29/8/2013

Flinders Care Plan & Health Summary

Review Due 1/11/2013

Personal Details														
Title:	Surname:	First Names:		Date of Birth:		Age: 68								
Address :										Gender: M				
Phone:		Mobile:		Occupation:		NHI:								
Doctor: Dr X - Oncology		Phone:		Preferred language:										
The key people (family/whānau/carers) I want included in my care plan are:														
Family and work colleagues														
I have problems with:						What motivates me and how I learn best: Reading								
<input type="checkbox"/> My hearing <input type="checkbox"/> My vision <input type="checkbox"/> Understanding English <input type="checkbox"/> Mobility <input type="checkbox"/> Reading/writing <input type="checkbox"/> Understanding numbers						Advanced Care Plan/ Power of Attorney / appointed? [please specify] Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/> If yes, provide details:								
Diagnoses & Active Problem List														
1.	Colorectal cancer T3 N2 M0			3.				5.						
2.	Hypertension			4.				6.						
Allergies (or Nil Known)														
1.				3.				5.						
2.				4.				6.						
Hospital Admissions / After Hour Clinics & ED Visits / Procedures														
Date	Hospital or Clinic			Reason			Notes							
July 2011	Wellington Hospital			Hernia repair										
July 2013	Wellington Hospital			Colorectal surgery										
Medication Record (including supplements, vitamins and over the counter medications)														
Generic or Trade Name	Strength	What Medication Is For	Frequency				Prescribing Health Provider	Date Started	Date Stopped	Comments				
			M	L	D	N								
Simvastatin	10mg	Cholesterol			X		GP							
Cardizem	180mg	Heart/BP			X		GP							
Accupril	20mg	Blood pressure			X		GP							
Loperamide		Diarrhoea					Hospital							
Furosemide	40mg	Fluid retention			X		GP							
Gastrosoothe	10mg	Abdominal spasms			X		Hospital							
Healthcare Team & Planned Visits/ Services for next 12 months From ___/___/___ To ___/___/___														
Role/Service	Name & Contact Details	No. Per Year	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
GP											X X	X		
Practice Nurse														
Specialist - Oncology											X	X		

Client /Patient Problem Statement: Side-effects, associated with cancer treatment, means I'm less productive than I used to be which makes me frustrated and angry.			How much of a problem is this for me? 0 1 2 3 4 5 6 7 8 Not at all Very little Somewhat A fair bit A lot (6 is marked)		
Client/Patient Goal Statement: In 2014, I will work to build my stamina in order to be able to address my productivity and work/life balance so I can indulge my interests and relax at times with things in order.			My progress towards achieving this goal 0 1 2 3 4 5 6 7 8 No success 25% 50% 75% success Complete (3 is marked)		
Identified Issues (Self-Management, Medical, Psychosocial, Whānau/Carer Support, Other)	Aims (What I want to achieve)	Interventions (Steps to Get There)	Who is Responsible?	Date to be reviewed	Progress (No progress, some progress, completed)
Main priorities – Work	Improve strength and endurance Address fatigue Build stamina	Sleep strategies Watch Dr Mike's youtube link on cancer-related fatigue (worksheet provided) Exercise – mowing lawn, walks with pets		At 6 week f/u appt	
Second priority – Family & Friends	Appreciate my family & friends for their support	Plan an after cancer 'new-normal' celebration meal Share my story to inspire others		Sep 2013 Ongoing	
Third priority – Be the best you, you can be!	Get back into life	Try something new. Rediscover an old interest. Volunteer your skills for a good cause. Carry on exploring authenticity and vulnerability.		Dec 2013 2014 Oct 2013	Referral to Cancer Society
Fourth priority - Getting house fixed up	Have a list of jobs	Do something, even if you do not feel like it. Go slow, try to plan to do a small amount per day or week and build up to usual routine		Dec 2013	
Cancer Recovery	Plan, prioritise and pace day-to-day activities during active treatment Do things you love to gain confidence	Pay attention to my symptoms and early warning signs (if treatment-related – contact cancer clinic) Be curious. Catch sight of the beauty around you. Be grateful. This helps to remind what matters most		Dec 2013 Ongoing	
Prevention	Stay cancer-free 'stack the odds in your favour'	Schedule visit with GP in 2014 to update him in person on cancer outcomes and interest in annual physicals and screenings		2014	
Questions, concerns	Identify my new normal (CancerConnect - 0800 CANCER)	The Cancer Society can put you in phone contact with another guy who has a similar experience of cancer, if you wish to discuss recovery and what 'normal' is like for them.		2014	

Appendix O: Research presentations and related articles

O'Brien IM, Sarfati D & Signal L. Supported self-management as a survivorship intervention: A phase I/II study with patients receiving colorectal cancer treatment in New Zealand. In MASCC Annual Scientific Meeting. Adelaide, Australia: June 2016

O'Brien IM. Cancer survivorship: Survivorship care pathways are needed in Aotearoa New Zealand. *Cancernet*, April 2016, pp. 5-6. Available from: <http://www.nzno.org.nz/Portals/0/Files/Documents/Groups/Cancer%20Nurses/Cancernet%20April%202016-3.pdf>

O'Brien IM. Hospital-based supported self-management intervention for colorectal cancer survivors: Acceptability and feasibility in New Zealand. In 2015 FCIC Survivorship conference. Adelaide, Australia: February 2015

O'Brien IM, Sarfati D, Signal L, Bycroft J, Lawn S and Koczwara B. Interventions to improve cancer outcomes for people with comorbidity. In COSA 41st Annual Scientific Meeting and 8th Annual World Cancer Congress. Melbourne, Australia: December 2014.

O'Brien IM, Sarfati D, Signal L, Bycroft J, Lawn S and Koczwara B. Self-management of comorbidity and recovery after colorectal cancer: A phase I/II study. In COSA 40th Annual Scientific Meeting. Adelaide, Australia: November 2013.

O'Brien IM, Sarfati D, & Signal L. Self-management support in cancer care pilot study: An integrated model-of-care and intervention protocol [Abstract #865]. In COSA 39th Annual Scientific Meeting and IPOS 14th World Congress of Psycho-Oncology (p. 353). Brisbane, Australia: November 2012.

CANCER SURVIVORSHIP

Survivorship care pathways are needed in Aotearoa New Zealand

Cancer and survivorship were once words with opposite meanings. In this day and age, more people live with cancer, than die from it. The increasing cancer survival rates are a great success story.

But, novel care pathways for this substantial population group have not evolved as quickly. Progress by survivor advocates, scientists, nurses and research participants have made advances in cancer diagnosis, treatment and survivorship possible.

Care pathway redesign to incorporate cancer survivorship is now a priority. The USA, UK, Canada and Australia have demonstration project or other survivorship initiatives in place. Although no demonstration project has worked seamlessly, each project adds to the rapidly evolving knowledge base on survivorship care. It is time for NZ to put in place survivorship care pathways and suggest quality-of-care indicators to enable evidence of pathway value to be explored.

History

Dr Fitzhugh Mullan coined the term 'cancer survivor' in his groundbreaking 1985 *New England Journal of Medicine* article, entitled **The Seasons of Survival**. He pointed out the need for advocacy by people living with and beyond cancer to address unmet needs over three time periods which he coined as seasons. He called these seasons of survival: acute survivorship, extended survivorship and permanent survivorship.

He described the category of acute

survival as beginning at diagnosis and extending through primary treatment when fear and anxiety were constant and heightened.

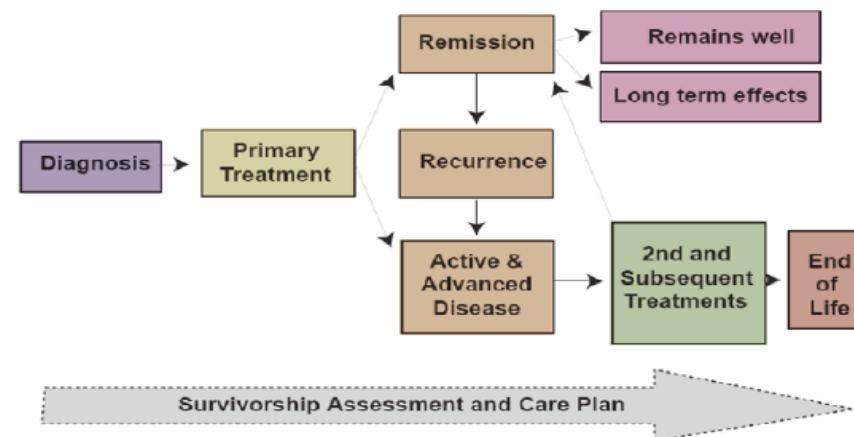
Extended survival began at the end of primary treatment when fear of recurrence and recovery from treatment-related physical limitations took place amidst periodic follow-up appointments.

Mullan's permanent survival season encompassed the five-year survival mark indicating "cure" but often with ever-present secondary impacts on mental and physical health.

As survivor advocacy and survivorship research progresses, so does the understanding of survivor seasons. Mullan's (1985) original stages of survivorship have been variously re-framed. This makes sense considering that cancer-related impacts, survival rates and unmet needs vary by cancer site and by population group. So, do these survivorship seasons work for NZ population groups?

In many countries, survivors have established formidable advocacy forces to get recognition for their ongoing needs. The needs of cancer survivors internationally are unique and not well understood. Most of the time, the impacts and needs are invisible but very real. Diverse groups of advocates have fought for resources and delivery of appropriate survivorship care to get unmet needs recognised and addressed.

Lance Armstrong made a phenomenal impact on cancer survivorship by using his celebrity status to raise awareness about the challenges of cancer survivorship.



Armstrong described feeling powerless after completion of treatment and unsure of what he was supposed to do to help himself. The foundation he began, now called LIVESTRONG, continues to be a great resource for cancer survivor information, support and advocacy.

Cancer survivors' experiences were described in the 2006 book on cancer survivorship, *From Cancer Patient to Cancer Survivor: Lost in Transition*. This book aimed to raise awareness of cancer survivorship, define quality health care for survivors, and identify strategies to improve the quality of life for survivors. It clearly showed that many people complete primary treatment relieved and overwhelmed but unaware of ongoing challenges, for example, fear of recurrence.

MacMillan Cancer Support in the United

Kingdom is another leader in the survivorship space. Their vision of working in this space is illustrated by the survivorship pathway that has evolved into a lateral or cyclical pathway beyond primary treatment.

Source: Department of Health, Macmillan Cancer Support and NHS Improvement, *NCSI Vision, 2010, p. 23*

It must be stated, that the tireless efforts of surgical, oncology, community and care coordinator nurses to provide quality cancer care amidst organisational and system challenges is phenomenal. But, it is not enough. The efforts of nurses alone to address cancer survivorship will fall short, no matter how hard you are trying, if systemic issues such as human resourcing, financing, IT capability and accountability for quality care are not addressed.



Survivorship care pathways are needed in Aotearoa New Zealand (CONTINUED)

NZ experience

NZ cancer survivorship is associated with health loss. Survivors face post-treatment challenges to physical health, finances, relationships, emotions, identity and future prospects. High-levels of uncertainty are present. NZ survivors show great strength in their efforts to keep calm and carry on.

Rising above the terminology debate on the applicability of the words 'cancer survivor' in NZ, NZ survivors need new care pathways to support them. Most cancer survivors are grateful for second chances and practice positive thinking but still need support to address ongoing or intermittent cancer-related morbidity or disability. Cancer survivorship 'ain't' easy, even with the documented associated possibilities for post-traumatic growth and new outlooks. Cancer care delivery in NZ has not systematically adapted to integrate support for people living with long-term cancer impacts.

Survivorship initiatives are underway. Some oncologists are using survivorship care plans as a way to provide a treatment summary and build awareness of potential survivorship issues for patients at the end of treatment. In addition, The Cancer Society's Otago/Southland division delivers a group programme developed by Otago University researcher Dr Sue Waltherth called Bridge to Health. Further, The Nelson Regional Breast & Gynaecological Trust makes available online A Survivorship Passport developed by NZ cancer survivor advocate, Andrea Fairbairn.

Although cancer has been traditionally treated as an acute condition in NZ, the trajectory of this group of diseases now consists of what can be described as a chronic phase. Life for cancer survivors is characterised by significant lingering

impacts on well-being, finances, social identity and family/workplace communication. Improved care pathways are needed.

Is cancer survivorship best served by classification as a chronic condition?

A recent PhD study by the author involved adaption and testing of a chronic care intervention in cancer care settings. The World Health Organisation classification of cancer as a chronic condition guided the choice of intervention. But, is cancer survivorship really a chronic condition?

To answer that question on whether cancer is best served by classification as a chronic condition, the value and applicability of using the Chronic Care Model to guide cancer survivorship care was explored. It is easy to draw a parallel between the illness experiences of people living with chronic conditions and cancer survivors. A diagnosis of a chronic condition and cancer both alter a person's physical and psychosocial health. They each impact on perceptions of identity and how people feel about themselves and how they feel perceived by others. Further, they each must be managed to prevent re-occurrence of acute symptoms and minimise adverse consequences. They impact on quality of life. Under the Chronic Care Model, survivorship care pathways would include supported self-management intervention, action plans, and partnership processes between general practitioners and survivors.

However, there are some important differences between cancer and other long-term chronic conditions that make the question of appropriate care pathway not so easy to answer. From the diagnosis of a chronic condition, the person diagnosed is treated as a co-partner in care

management and considered an expert in their illness. For cancer survivors, this is not the case because it is not realistically possible for survivors to take equal responsibility for managing their illness from diagnosis when a speedy response is needed. In addition, the complexity of cancer treatment pathways are very different from most chronic illness care pathways. Further, the impact on identity is more severe due to cancer survivors' normal contemplation of death as a possible outcome and the common condemnation or advice received from others over lifestyle choices.

The conclusion proposed is that despite cancer having aspects in common with other chronic illnesses, cancer survivor experiences are distinctive. The categorization of cancer as a chronic illness may downplay important acute experiences and impacts from the cancer experience. This complicates the view on which approach to survivorship care pathways best serve survivors' needs and desires to move forward.

Models of survivorship care

The delivery of any cancer survivorship pathway needs to fit with the predominant existing models of care in NZ. The main models of health care and delivery, as influenced by the predominant publicly-funded health care system, can be described as disease-centred care, person-centred care and Māori-whānau centred care. In general, within each of these models, the workforce, infrastructure and culture impact on interventional approaches and care delivery.

The majority of published survivorship research centres around the themes of shared care, survivorship care plans and

supported self-management intervention. Shared care involves a planned and formalised process of transition for the cancer survivor from oncologist care to general practitioner care. Survivorship care plans include a treatment summary and a patient-driven care plan. Supported self-management intervention in cancer care incorporates self/whānau-assessment surveys, guided interviews/sessions, and care plans to empower people to better manage survivorship transitions. The survivors' and families' values, priorities and goals guide negotiated actions documented in a person-centred care plan.

So, in answer to the question: Should cancer survivorship care in NZ follow an oncology pathway, a chronic condition pathway or a shared care pathway? The answer is not clear. What is needed is further research and the development of a cancer survivor risk stratification tool that takes into account diversity in culture, priorities, health complexity and life complexity. It is difficult to conceptualise a 'one-size fits all' care pathway considering the diversity and complexity of survivors' experiences and priorities.

Cancer survivorship may be delivered in an acute rehabilitation model, guided by a chronic care model or as a shared care model. There is no right approach. It is worth considering weekend survivorship clinics based in cancer centres and Cancer Societies. The focus of moving forward survivorship clinics could include a combination of illness-related work, biographical work and practical support. Survivorship care is needed in NZ and this would be a start.

Inga O'Brien, Supportive Care Manager and Deputy CEO, Cancer Society, Wellington